DOCUMENT RESUME

ED 292 248 EC 202 030

TITLE	Catastrophic Health Insurance: The Needs of Children. Joint Hearing before the Subcommittee on Health and Long-Term Care of the Select Committee on Aging and the Select Committee on Children, Youth, and Families. House of Representatives, One Hundredth Congress, First Session.
INSTITUTION	Congress of the U.S., Washington, DC. House Select Committee on Children, Youth, and Families.
PUB DATE	23 Mar 87
NOTE	298p.; Aging Committee Pub. No. 100-629. Parts of the document contain small print.
AVAILABLE FROM	Superintendent of Documents, Congressional Sales Office, U.S. Government Printing Office, Washington, DC 20402.
PUB TYPE	Legal/Legislative/Regulatory Materials (090)
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	*Disabilities; *Diseases; Early Childhood Education; Elementary Secondary Education; *Federal Aid; *Federal Legislation; *Financial Support; *Health Insurance; Health Services; Hearings; National Organizations; Pediatrics; Personal Narratives
IDENTIFIERS	*Catastrophic Insurance

ABSTRACT

This joint hearing, held on March 23, 1987, focused on the needs of chronically ill children for catastrophic health insurance. The first panel included the personal accounts of young Americans with chronic health problems, their parents, and a spokesperson from the National Foundation for Home Care. The second panel illustrated the dimension of the problem and included presentations from the Foundation for Hospice and Home Care, American Academy of Pediatrics, Western Association of Children's Hospitals, and National Maternal and Child Health Resource Center. The third panel outlined responses to the catastrophic health care needs of children, prepared by representatives from the Children's Defense Fund, National Association of Children's Hospitals and Related Institutions, and Consortium for Citizens with Development Disabilities. The appendix, which comprises nearly half the document, contains correspondence, reports, and prepared statements from a member of Congress, national organizations, a medical school, and concerned citizens. (JDD)

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CATASTROPHIC HEALTH INSURANCE: THE NEEDS OF CHILDREN

JOINT HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

OF THE

SELECT COMMITTEE ON AGING

AND THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES
HOUSE OF REPRESENTATIVES

ONE HUNDREDTH CONGRESS

FIRST SESSION

MARCH 23, 1987

Printed for the use of the Select Committee on Aging and the Select Committee on Children, Youth, and Families

Aging Committee Pub. No. 100-629

ED292248

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CONTENTS

Members Opening Statements

	Page
Chairman Claude Pepper	1
Chairman George Miller	6
Mary Rose Oakar	11
Ike Skelton	16
J. Roy Rowland	16
George C. Wortley	18

Chronological List of Witnesses

Panel One—Younger Americans With Chronic Health Problems:	
Susan Sullivan, actress, Los Angeles, CA; and spokesperson for National Foundation for Home Care, Washington, DC	19
Randy Kramer, Miami, FL	23
Angie Bachschmidt, Washington, DC; on behalf of her son Robert, age 4	26
Tracy Sutton, Phoenix, AZ; on behalf of her son Alex, age 3	27
Sandy Reckeweg, Waldorf, MD; on behalf of her son Jeff, age 5	28
Joe Miller, Los Angeles, CA	32
Steven Brown, Bethesda, MD	33
Diane Fleming, Bethesda, MD	34
Deborah Russell, Kalamazoo, MI; on behalf of her son Daniel	37
Rev. Robert K. Massie, Jr., Boston, MA	40
Panel Two—The Dimension of the Problem:	
Hon. Frank Moss, former U.S. Senator; and chairman, board of trustees, Foundation for Hospice and Home Care, Washington, DC	52
Hon. Charles H. Percy, former U.S. Senator; and vice chairman, board of trustees, Foundation for Hospice and Home Care, Washington, DC	56
James Perrin, M.D., director, Ambulatory Care Programs, Children's Service, Massachusetts General Hospital, Boston, MA; on behalf of the American Academy of Pediatrics	61
J.D. Northway, M.D., president and chief executive officer, Valley Children's Hospital, Fresno, CA; on behalf of Western Association of Children's Hospitals	76
Josephine Gittler, J.D., codirector, National Maternal and Child Health Resource Center, University of Iowa, Iowa City, IA	83
Panel Three—The Response to the Catastrophic Health Care Needs of Children:	
Sara Rosenbaum, director, child health, Children's Defense Fund, Washington, DC	97
Constance U. Battle, M.D., medical director and chief executive officer, the Hospital for Sick Children, Washington, DC; on behalf of National Association of Children's Hospitals and Related Institutions	112
Robert H. Sweeney, president, National Association of Chidren's Hospitals and Related Institutions, Alexandria, VA	113
Michael Morris, executive director, United Cerebral Palsy Association; on behalf of Consortium for Citizens with Development Disabilities, Washington, DC	119

Appendix

"The Crisis of Chronically Ill Children in America: Triumph of Technology—Failure of Public Policy," a report by the Caring Institute of the Foundation for Hospice and Homecare	129

Page

Association of Maternal and Child Health Programs, prepared statement 249
Hon. Tony Coelho, a Member of Congress from the State of California, prepared statement 252
"Insurance Coverage for Developmentally Disabled Children," a study prepared by the Rose F. Kennedy Center, UAF, Albert Einstein College of Medicine, Bronx, NY 255
Alberta Miller, prepared statement 259
Alan J. Mittelman, J.D., CLU, attorney at law, Jenkintown, PA, letter 260
"Catastrophic Illness Expense and Children," a statement by the National Association of Children's Hospitals and Related Institutions, Inc., Alexandria, VA 263
Sally A. Mack, LICSW, Chair, Social Action Committee, National Association of Perinatal Social Workers, Chestnut Hill, MA, letter 276
Jennifer M. Cernoch, Ph.D., director, Texas Respite Resource Network; and Marian Sokol, Ph.D., director, Project ABC, letter and prepared statement ... 278
American Hospital Association, prepared statement 285

CATASTROPHIC HEALTH INSURANCE: THE NEEDS OF CHILDREN

MONDAY, MARCH 23, 1987

HOUSE OF REPRESENTATIVES, SELECT COMMITTEE ON CHILDREN, YOUTH AND FAMILIES, AND THE SELECT COMMITTEE ON AGING, SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE,

Washington, DC.

The Select Committee and Subcommittee met, pursuant to notice, at 10:10 a.m., in room 2322, Rayburn House Office Building, the Hon. George Miller (Chairman of the Select Committee on Children, Youth, and Families) and the Hon. Claude Pepper (Chairman of the Subcommittee on Health and Long-Term Care of the Select Committee on Aging) presiding.

Members present: Representatives Miller, Pepper, Oakar, Skelton, Rowland, and Vento.

Staff Present: Ann Rosewater, staff director; Jill Kagan, professional staff; Darcy Coulson Reed, minority research staff; Spencer Kelly, minority research staff; Joan Godley, committee clerk; of the Select Committee on Children, Youth, and Families.

Kathy Gardner Cravedi, staff director; Melanie Modlin, assistant staff director; Peter Reinecke, research director; Judy Whang, staff assistant; Lil Simmons, volunteer; Martha Messmer, intern; Amy Beaulieu, intern; Mark Benedict, minority staff director; and Doug Maragas, minority assistant staff director; of the Subcommittee on Health and Long-Term Care.

OPENING STATEMENT OF CHAIRMAN CLAUDE PEPPER

Chairman PEPPER. The committee will come to order, please.

Ms. Oakar, Mr. Miller, and I wish to welcome all of you here this morning to attend this very important hearing. It has to do with catastrophic care as needed by the children of this country—too long and too much neglected. We're trying in this session of Congress to do something that should have been done long ago.

In 1938 a great Senator from the State of New York, Senator Robert Wagner, introduced in the Senate a bill for comprehensive care for all the people. Nothing was done about it. In 1945, President Harry S Truman sent to the Congress a request that the Congress enact a comprehensive health care program for all the people of our country. Nothing was done about it. A year later, the Wartime Health and Education Select Committee, of which I was chairman, came up with a similar recommendation, as well as programs

of research, hospital building and the like. Nothing was done about it for 20 years.

Finally, in 1965, Congress enacted the medicare legislation. It was a great step forward. It did provide hospital care up to 2 months for people who had serious illness and could be treated on an emergency basis. It meant much to many in our country especially to the elderly, but it did not cover hospitalization beyond 2 months and it did not cover nursing home care; it did not cover home care; it did not cover drugs—on which the elderly alone spend $10 billion a year; it did not cover eyeglasses or hearing aids; it did not cover dental care and dentures, nor did it cover foot care for the elderly. And, of course, it did not cover, except for the families of the very destitute, the children of the country.

Now then, in 1986, in his message to Congress, the President said—and we were so hopeful when we heard those words—we must enact a catastrophic care program for people of all ages. But unfortunately, when the administration made its recommendation to the Congress this year, that program was limited by the so-called Bowen bill to only those who stayed in the hospital more than 2 months, which the authorities tell us is way below 3 percent of all the people on medicare. It does nothing for the children. No home care, no nursing home care, and no custodial care. None of these other needs that I have mentioned.

So today, we're going to have a graphic presentation of the health care needs of the children of this country and the inadequacy of what's been proposed so far.

Let me just refer to two of the witnesses that you will hear today.

For example, we will hear from the parents of 3-year-old Alex Sutton of Phoenix, Arizona. Alex is a victim of a degenerative, terminal illness known as Tay-Sachs which causes a breakdown of the brain's functioning. Alex is subject to several seizures a day and has a complicated regimen of medications to control them. His family waged a long battle to get home health care from their insurance company and finally won. However, the policy only covers 80 percent of the total costs, and 20 percent of the $200,000 to $250,000 in annual costs the family must bear is still considerable.

I mention one other case who is here today. A young man suffers from a chronic breathing disorder. He often stops breathing when he is asleep. He requires very specialized care to stay alive. As a result, Jeff Reckeweg has spent his life in and out of hospitals. The costs of his care are astronomical, around $600,000 a year for hospital care and another $150,000 a year for care at home. Jeff's $100,000 health insurance policy was exhausted in less than 9 months.

Since then his parents have gone in debt by $800,000. Their only salvation is that the State of Maryland created a special program of assistance for Jeff. However, we cannot be assured that program will continue for a long time.

So we, today, are going to hear graphic, heart-rending stories of the inadequacies of the laws of our land today and how this compassionate America, this powerful and rich America, is so neglectful of the crying needs of those who deserve so much from it.

So now may I present to you my distinguished colleague who is Chairman of the Select Committee on Children, Youth, and Families in the House and doing a magnificent job on behalf of the children of this country. This is a joint hearing between his Committee and our Subcommittee on Health and Long-Term Care. May I present the Honorable George Miller of California.

[The prepared statement of Chairman Pepper follows:]

OPENING STATEMENT OF CHAIRMAN CLAUDE PEPPER

LADIES AND GENTLEMEN. IT IS A PLEASURE TO JOIN MY DISTINGUISHED COLLEAGUE GEORGE MILLER OF CALIFORNIA, AND THE MEMBERS OF HIS SELECT COMMITTEE ON CHILDREN, YOUTH AND FAMILIES IN CONVENING THIS IMPORTANT HEARING. I HOPE THAT OUR COMING TOGETHER TODAY WILL HELP DEMONSTRATE THAT CATASTROPHIC ILLNESS KNOWS NO AGE. WHETHER YOUNG OR OLD, ONCE STRICKEN WITH A CHRONIC ILLNESS -- A CONDITION WHICH ONE HAS NO REASONABLE EXPECTATION OF RECOVERY -- ONE CAN EXPECT FEDERAL, STATE OR PRIVATE INSURANCE TO COME TO AN END.

OUR CONCERN FOR THE PLIGHT OF OUR NATION'S CHRONICALLY ILL YOUTH IS PARTICULARLY TIMELY IN LIGHT OF THE PRESIDENT'S RECENT PROPOSAL TO COVER THE CATASTROPHIC HEALTH CARE NEEDS OF THE AGED. WHILE MOST AGREE THAT HIS PLAN WOULD HELP ONLY ABOUT 3 PERCENT OF THE 31 MILLION ELDERLY AND DISABLED OF AMERICA, IT WILL NOT HELP OUR 70 MILLION YOUNGER AMERICANS AT ALL, 10 MILLION OF WHOM ARE CHRONICALLY ILL.

WHILE I AM PLEASED THAT THE PRESIDENT NOW AGREES THAT WE MUST ASSIST OUR ELDERLY AGAINST THE BANKRUPTING COSTS OF A CATASTROPHIC ILLNESS, I AM DISTURBED THAT HE CHOSE TO ABANDON HIS PLAN -- AS HE OUTLINED TO THE NATION IN HIS 1986 STATE OF THE UNION MESSAGE -- TO ASSIST PERSONS "OF ALL AGES." WHAT THE PRESIDENT HAS PROPOSED WITH RESPECT TO HELPING THE VICTIMS OF CATASTROPHIC ILLNESS IS NOTHING SHORT OF A NATIONAL DISGRACE. IT IS A DISGRACE FOR THE YOUNG OF AMERICAN BECAUSE IT WON'T COVER THEM. IT IS A DISGRACE FOR THE ELDERLY OF AMERICA BECAUSE IT DOES NOT BEGIN TO ADDRESS THEIR CATASTROPHIC HEALTH CARE NEEDS. THE PRESIDENT'S PLAN WON'T PAY FOR NURSING HOME CARE, CUSTODIAL CARE IN THE HOME, OUT-OF-HOSPITAL PRESCRIPTION DRUGS, HEARING CARE, EYE CARE, DENTAL CARE, FOOT CARE OR ROUTINE PHYSICAL EXAMS. ALL THE PRESIDENT'S PLAN WILL DO IS HELP OLDER AMERICANS STAY IN A HOSPITAL LONGER. 97 PERCENT OF THE AGED IN AMERICA WOULD NOT BENEFIT UNDER THE PRESIDENT'S PLAN.

TESTIMONY TODAY WILL HIGHLIGHT THE FACT THAT PROVIDING COVERAGE FOR LONG HOSPITAL STAYS IS NOT ONLY COSTLY, IT TEARS FAMILIES APART. FOR EXAMPLE, WE WILL HEAR TODAY FROM THE PARENTS OF 3 YEAR OLD ALEX SUTTON OF PHOENIX, ARIZONA. ALEX IS A VICTIM OF A DEGENERATIVE, TERMINAL ILLNESS KNOWN AS TAY-SACHS WHICH BRINGS ON A BREAKDOWN OF THE BRAIN'S FUNCTIONING. ALEX IS SUBJECT TO SEVERAL SEIZURES A DAY AND HAS A COMPLICATED REGIMEN OF MEDICATIONS TO CONTROL THEM. HIS FAMILY WAGED A LONG BATTLE TO GET HOME HEALTH CARE FROM THEIR INSURANCE COMPANY AND FINALLY WON. HOWEVER, THE POLICY ONLY COVERS 80% OF THE TOTAL COSTS, AND THE 20% OF $200,000 TO $250,000 IN ANNUAL COSTS THE FAMILY MUST BEAR IS STILL CONSIDERABLE.

WE WILL ALSO HEAR FROM 5 YEAR OLD JEFF RECKEWEG OF CLINTON, MARYLAND. HE SUFFERS FROM A CHRONIC BREATHING DISORDER. HE OFTEN STOPS BREATHING WHEN HE IS ASLEEP. HE REQUIRES A VERY SPECIALIZED CARE TO STAY ALIVE. AS A RESULT, HE HAS SPENT HIS LIFE IN AND OUT OF HOSPITALS. THE COSTS OF HIS CARE ARE ASTRONOMICAL -- AROUND $600,000 A YEAR FOR HOSPITAL CARE AND $150,000 A YEAR FOR CARE AT HOME. JEFF'S $100,000 HEALTH INSURANCE POLICY WAS EXHAUSTED IN LESS THAN 9 MONTHS. SINCE THEN, HIS PARENTS HAVE GONE IN DEBT BY $800,000. ONLY THE STATE OF MARYLAND CREATED A SPECIAL PROGRAM OF ASSISTANCE FOR JEFF, SO HE IS TEMPORARILY BEING ASSISTED WITH HOME CARE. HOWEVER, THIS ASSISTANCE COULD END AT ANY TIME, LEAVING THE RECKEWEG'S WITH HEALTH CARE COSTS THEY SIMPLY CAN'T AFFORD.

WE WILL HEAR THESE AND OTHER TRAGIC PERSONAL ACCOUNTS OF YOUNGER AMERICANS WHOSE LIVES HAVE BEEN TOUCHED BY THE BANKRUPTING COSTS OF A CATASTROPHIC ILLNESS. WE WILL ALSO HEAR FROM MS. SUSAN SULLIVAN, THE STAR OF "FALCON CREST" AND SPOKESPERSON FOR THE FOUNDATION ON HOSPICE AND HOME CARE WHICH IS PIONEERING THE FIELD OF PEDIATRIC HOME CARE IN AMERICA.

I ALSO LOOK FORWARD TO HEARING FROM MY DISTINGUISHED FORMER COLLEAGUES, SENATORS FRANK MOSS AND CHARLES PERCY. AS THE CO-CHAIRS OF THE FOUNDATION OF HOSPICE AND HOME CARE THEY WILL JOIN US TODAY TO RELEASE THEIR NATIONAL REPORT WHICH WILL PROVIDE DEFINITION TO THE PLIGHT OF FRAIL CHILDREN. THIS REPORT WILL DETAIL HOW PARENTS OF CHRONICALLY ILL CHILDREN FACE AN IMPOSSIBLE DILEMMA. THEY CAN EITHER LEAVE THEIR CHILDREN IN THE HOSPITAL OR IN AN INSTITUTION AND KNOW THE STAGGERING BILLS WILL BE PAID OR THEY CAN TRY TO BRING THEM HOME AND HOPE THEY AND AVOID JOINING THE 1 MILLION AMERICANS WHO WILL FALL INTO POVERTY THIS YEAR DUE TO THE CATASTROPHIC COSTS OF THE HEALTH CARE THEY MUST SECURE.

LASTLY WE LOOK FORWARD TO HEARING FROM THOSE WHO REPRESENT YOUNGER AMERICANS, THEIR HEALTH CARE PROVIDERS AND REPRESENTATIVES OF CHILDREN'S HOSPITALS WHERE CARE FOR THE CHRONICALLY ILL IS OFTEN PROVIDED. I AM INTERESTED IN HEARING THEIR VIEWS ON THE ADMINISTRATION'S PROPOSAL ON CATASTROPHIC HEALTH CARE INSURANCE, ITS SHORTCOMINGS AND THE MERITS OF PROVIDING REAL, MEANINGFUL, COMPREHENSIVE AND CATASTROPHIC HEALTH CARE.

I HAVE INTRODUCED LEGISLATION, H.R. 65, WHICH WILL PROVIDE THE ELDERLY PEOPLE OF THIS COUNTRY WITH COMPREHENSIVE CATASTROPHIC HEALTH CARE PROTECTION BOTH IN AND OUT OF A HOSPITAL AT NO GREATER COST TO THE ELDERLY PEOPLE OF THIS COUNTRY OR TO THEIR COUNTRY. I INTEND TO INTRODUCE ANOTHER BILL WITHIN SEVERAL WEEKS WHICH WILL EXTEND THIS PROTECTION TO PERSONS BELOW THE AGE OF 65.

WHY DO WE KEEP ON COMPROMISING WITH TRAGIC NECESSITY AND ALLOW MILLIONS OF AMERICANS TO DIE WITHOUT THE MEDICAL CARE THEY NEED OR TO SUFFER DEVASTATING FINANCIAL DISTRESS WHEN A DECENT AMERICAN PLAN SUCH AS H.R. 65 MIGHT BE IMPLEMENTED. I HAD HOPED THAT THE PRESIDENT WOULD THROW ASIDE THE SHACKLES WHICH SURROUND HIM IN RESPECT TO THIS MATTER AND TAKE A BOLD POSITION FOR WHICH AMERICA WOULD BE EVER GRATEFUL TO HIM. HE HAS A CHANCE TO ENDEAR HIMSELF TO THE AMERICAN PEOPLE EVEN MORE THAN PRESIDENT ROOSEVELT ENDEARED HIMSELF BY GIVING THEM SOCIAL SECURITY.

I HOPE TO LIVE TO SEE THE DAY WHEN IN OUR BLESSED AMERICA EVERY MAN, WOMAN, AND CHILD WOULD BE ASSURED OF GETTING THE MEDICAL CARE THAT HE OR SHE SHOULD HAVE. I THINK THAT IS A PART OF THE AMERICAN DREAM, AND THAT IS A PART OF THE AMERICAN GOAL.

OPENING STATEMENT OF CHAIRMAN GEORGE MILLER

Chairman MILLER. Thank you, Mr. Chairman.

I am pleased to be here today with Chairman Claude Pepper in a joint hearing because I think it will graphically show that chronic catastrophic illnesses and disabilities show no discrimination on the basis of age.

We will hear from our first panel this morning that children are especially vulnerable as are the families in which they live. There are 35 million Americans without insurance; one-third or 11 million of them are children. What we see is in fact children, because of the situation of their parents, most often are not covered by health insurance programs.

Nearly 30 percent of those children who have no health care coverage have parents who are, in fact, covered by employer sponsored programs, but they do not cover their children.

I think that we see no greater issue that confronts long-term family stability in this society than this one of how we handle long-term illnesses and catastrophic illnesses. More often than not, what we see is that many families are put in the position of choosing the well being of their family—the bankruptcy wiping out their savings and totally altering the structure of their family to accommodate these proceedings because they cannot meet the financial obligations that occurred as they tried to deal compassionately with the illnesses suffered by their children.

I would hope that as the Congress continues to deliberate the notion of catastrophic care, we would understand that, in fact, it must be extended to all of those families that find themselves in this situation and I look forward to hearing from the panelists.

[The prepared statement of Chairman Miller follows:]

PREPARED STATEMENT OF CHAIRMAN GEORGE MILLER

Today, I am pleased to be here with Chairman Claude Pepper in a joint hearing of the Select Committee on Children, Youth, and Families and the Select Committee on Aging.

The President asks us to believe that his initiative would protect those most vulnerable to catastrophic illness.

But his proposal would protect only a fraction of the elderly, and none of the millions of young Americans who have a chronic illness or no health insurance.

Debilitating illness or disability does not discriminate on the basis of age. And today, the frightening reality is that more of us are unprotected than ever before.

Children are especially vulnerable. Of the 35 million Americans without any health insurance, one-third - 11 million - are children. Millions more children have health care coverage that would leave them completely unprotected in the event of a catastrophic illness, even if their parents are fully employed.

Nearly 30% of today's uninsured children have employed parents with employer-sponsored health plans -- but the plans do not cover their children. This scenario will worsen as increasing numbers of new jobs are in the traditionally low-wage, low-benefit service sector.

For the poorest children, public programs fail to provide adequate, if any coverage: millions of poor children are not covered at all, and millions more are not protected against the costs of catastrophic care.

Fewer than half of all poor children, and only 60% of low-income disabled children, are covered by Medicaid. And for low-income families, the cost of routine medical care or care for a minor illness or surgery can be catastrophic.

Few issues are of greater concern to this nation than ensuring family stability. Yet the stability of millions of American families is at risk because a child's illness or disability has severely strained their finances, and in many cases, has forced them into poverty.

More often than not, families with chronically ill or disabled children are denied health insurance when they need it most, face extraordinary out-of-pocket medical expenditures that wipe-out savings or result in family bankruptcy, or are forced to choose between poverty or their child's institutionalization.

Each of these situations undermines the fabric of family life, and generates enormous public costs. About 2 percent of the children in America use 20-30% of child health expenditures. And, as we will learn today, in California alone, one half of one percent of all hospital admissions of children cost $280 million, or 22% of hospital costs for the state's children.

Today, we will hear from children and families who have experienced the devastation of catastrophic illness. They will help insure that the public debate over catastrophic health care does not ignore the millions of children and families who are just as vulnerable as the elderly, and perhaps more.

I welcome all of our witnesses here today, and appreciate your contribution to our efforts to expand health care protections for vulnerable children and families.

FACT SHEET
CATASTROPHIC ILLNESS AND LONG-TERM CARE:
ISSUES FOR CHILDREN AND FAMILIES

EXTENT OF CHRONIC ILLNESS AMONG CHILDREN

*Approximately ten million children (10-15% of all children) have a chronic illness; about one million have a severe chronic illness. (Gortmaker and Sappenfield, 1984)

*Between 1960 and 1981, the prevalence of activity-limiting chronic conditions among children under age 17 doubled, from 1.8% to 3.8%. Respiratory conditions and mental and nervous system disorders demonstrated the largest changes. (Newacheck, Budetti, and Halfon, 1986)

*Prematurity is anticipated in 6 births per 1000; cystic fibrosis in 1 birth per 1000; congenital heart disease in 7.5 births; and a diagnosis of cancer in 130 children per 1 million. (National Association of Children's Hospitals and Related Institutions [NACHRI], 1986.)

*Prevalence rates of certain diagnostic groups may have increased as a result of improved chances for survival. The evidence suggests a sevenfold increase in survival to age twenty-one among children with cystic fibrosis, and increases of twofold or greater for children with spina bifida, leukemia, and congenital heart disease. In 1984, the survival rate for childhood cancer was over 54%, compared to 39% in 1970. (Gortmaker, 1985; American Cancer Society, 1984)

*Poor children are 40% more likely to have a severe functional disability than do children in families with higher incomes (8.5% vs. 4.9%). (NACHRI, 1986)

CHRONICALLY ILL CHILDREN HAVE HIGH MEDICAL COSTS

*The cost of care for very distressed, ventilator dependent infants who remain hospitalized can reach $350,000 per year. (NACHRI, 1986)

*The annual expenses for hospital and physician services for a child with a disabling chronic condition has been estimated to range from $870 to $10,229, depending on the severity of the illness. In contrast, the typical healthy child's expenses for these services average about $270 a year. (Fox, 1984)

*In 1980, more than $1.7 billion were expended for physician visits and hospitalization of children with activity limitations; hospitalization accounted for 65% of the total. The average annual hospital cost for a child with activity limitation was $511 compared with only $66 for a child without limitations. (Butler, et al, 1985)

*Comprehensive care for a child with cystic fibrosis can cost a family $6,000-12,000 annually; and intermittent hospitalizations may average over $7,000 per stay. (NACHRI, 1987)

- over -

*Expenses for a child with cerebral palsy, including physician services, speech therapy, medications, special education, and other support services average $4490 annually, with 51% paid by the family. (United Cerebral Palsy Association, 1986)

ACUTE OR PRIMARY HEALTH CARE COSTS FOR CHILDREN HIGH

*In 1985, newborn intensive care costs totaled $2.4-$3.3 billion and averaged $14,698 for each infant. (American Academy of Pediatrics [AAP], 1986)

*Cardiac surgery for a child may cost a family $22,000 for a hospital stay. (NACHRI, 1987)

*Treatment for extensive burns may result in a hospital bill of $45,000. (NACHRI, 1987)

*The $600 cost of treatment for one asthma episode, or a routine hospitalization costing $700 per day, may be catastrophic for those with no insurance or very limited resources. (NACHRI, 1987)

SMALL PERCENTAGE OF CHRONICALLY ILL CHILDREN INCUR HIGH PERCENTAGE OF MEDICAL EXPENSES

*Fewer than 1 million or 1% of all children under 21 are likely to incur catastrophic expenses if catastrophic is defined as out-of-pocket medical expenses greater than 10% of family income. (AAP, 1986; Newacheck, 1986)

*About 5% of all children incur annual medical costs in excess of $5,000. Others estimate that 5-10% of children incur catastrophic expenses in excess of $10,000 (regardless of insurance coverage). (Rosenbaum, 1987; AAP, 1987)

*In 1983-84, the 1.35% of admissions to children's hospitals incurring catastrophic expenses over $50,000 accounted for 26% of the total children's hospitals' inpatient charges. Newborns accounted for 50% of these hospital admissions. (NACHRI, 1987)

*In 1980, the total cost for hospitalization of children with activity limitations ($1.17 billion) was 30% of the total hospital care costs ($3.86 billion) for all children. (Butler, 1985)

MILLIONS OF CHILDREN WITH NO HEALTH INSURANCE

*In 1985, 11 million children age 18 or younger were uninsured. Among uninsured children, 64% lived in families headed by someone without health insurance; 29% lived in families headed by someone with employer-based health coverage, usually a parent. (Employee Benefits Research Institute [EBRI], 1987)

*Three-quarters of all uninsured children have family incomes below 200% of the federal poverty level, and between 66-75% live in working families. (Rosenbaum, 1987)

*In 1985, nearly half of the uninsured children age 18 or under lived in single-parent, usually female-headed, families. (EBRI, 1987)

*Children without any form of health insurance protection were most likely to be Hispanics and near poor children whose family incomes were between 100 and 200% of poverty. Children living in the South and West and in the rural areas were more likely than those in other regions and communities to lack coverage. (Butler, 1985)

*10.3% of disabled children, and 19.5% of disabled children in poverty have no health insurance. (Butler, 1985)

*Forty percent of all disabled children below the federal poverty level are not covered by Medicaid. Private group and individual insurance covers about 60% of disabled children, compared to 75% in the general child population. (Butler, 1985)

*In FY 1985, Medicaid served 10.9 million children younger than 21 -- more than 400,000 fewer than were served in FY 1978. (Rosenbaum, 1987)

*Uninsured low-income children receive 40% less physician care and half as much hospital care as insured children. (Rosenbaum, 1987)

MILLIONS OF CHILDREN WITH INADEQUATE INSURANCE

*Of those children under 18 who are insured, 17% do not have major medical to cover special health care costs, and less than 10% have unlimited coverage. (NACHRI, 1987)

*Of all employers responding to a major health insurance survey conducted in 1986, 73% indicated that their plans excluded coverage of pre-existing conditions. Only about 75% of plans offered by medium and large-sized firms between 1980 and 1985 contained protections against huge out-of-pocket costs borne by enrollees in the event of catastrophic illness. (Rosenbaum, 1987)

*Fourteen state Medicaid programs limit the number of hospital days covered each year, and 15 states restrict the number of covered physician visits. (Rosenbaum, 1987; Fox, 1984)

Chairman PEPPER. Thank you very much, Mr. Miller.

And now we will hear from that distinguished member of our Subcommittee on Health and Long-Term Care, Ms. Oakar of Ohio.

STATEMENT OF REPRESENTATIVE MARY ROSE OAKAR

Ms. OAKAR. Thank you very much, Mr. Chairman.

Mr. Chairman and Chairman Miller, first of all I want to compliment both of you. I have always thought that health issues are family issues and it's really a wonderful tribute that you could have a hearing to show that the needs of the elderly are not unlike the needs of the children of our country.

Mr. Chairmen, I have just seen a very poignant film. It began about a half hour ago and was called "Suffer Not the Little Children." Many of our distinguished panelists today are the stars, in quotation marks, of that film.

We're proud of their families for coming forward to allow their situation to be nationally known, because that way we can call attention to the problem.

I want to compliment Susan Sullivan, one of the great actresses of our time. I'm especially proud of her, not only because of the work that she does in this direction—speaking out on children's issues, hospice care and other kinds of difficulties—but also because she started her career at the Cleveland Playhouse in my district. We're proud of that, Susan. I'm not sure that was the springboard for all your success, but we're especially proud of that.

One area that I would just like to briefly discuss is a bill I've introduced that relates to long term care for the elderly. When we wrote this bill, we took a comprehensive notion about health care and included the services that people need whether it's home care or various therapies. The fact is that this approach is cheaper. It makes sense to deal with the situation of treating chronically ill in this reasonable fashion.

The other point that I would briefly like to make, in my opening statement, is that I was very, very chagrined when I found out from one of the member's wives, Camilla Walgren, that at NIH, which as you know very often does experimental research with those people who are terminally ill, who are the so-called hopeless cases that want hope, there are about 40 children in one of the cancer wards over there. These children received therapy that makes them bald. Some are amputees, some and have burns from radiation and are swollen, and they range from ages of about 2 or 3 to about 11 or 12. One of the things that the Inspector General of HHS has done recently is to rule that these kids could not have what is to them a lifeline, their phone service—so that they could call their friends at school or their families. Most of them are pretty much alone and I think that the telephone service is as the doctors said, part of their therapy. I would just hope that NIH and the Inspector General understand that having those phones, their lifeline, is part of the treatment for their illness and it gives them a sense of hope and comraderie when they can talk to their loved ones. It also takes a lot of the stress away that is very often related to cancer.

So today, I hope that my distinguished Chairmen who have already, I think, called about this and I know Jim Wright, the Speaker, is very concerned about this, I hope that we can all work together and do something today to restore that toll-free ability for these people to call their loved ones. These kids, I'll tell you, will really do something very, very positive in a short time, so I call on NIH to restore that service. Otherwise we'd have to do a little line item or something that doesn't make a lot of sense to have that kind of a fight when it's so doable.

So I want to thank both of you and compliment you and I look forward to working with you on these and other issues. Thank you.

[The prepared statement of Representative Oakar follows:]

PREPARED STATEMENT OF REPRESENTATIVE MARY ROSE OAKAR

CHAIRMAN MILLER, CHAIRMAN PEPPER, DISTINGUISHED GUESTS. I AM VERY PLEASED TO BE A PART OF THIS HEARING THIS MORNING. THE ISSUES OF CATASTROPHIC HEALTH CARE ARE VITAL ONES THAT WE MUST DISCUSS. AS A MEMBER OF THE SELECT COMMITTE ON AGING, I HAVE LONG FOUGHT TO SEE THAT ADEQUATE HEALTH COVERAGE IS PROVIDED FOR OUR ELDERLY POPULATION. AS A MEMBER OF THE POST OFFICE AND CIVIL SERVICE COMMITTEE I HAVE LONG FOUGHT TO PROVIDE ADEQUATE COVERAGE FOR OUR FEDERAL EMPLOYEES. AND I AM HERE TODAY TO SAY THAT WE MUST ALSO HELP CHILDREN AND THEIR FAMILIES WHO FACE CATASTROPHIC ILLNESS TO DEAL WITH THE FINANCIAL PRESSURES THAT THAT ILLNESS CAUSES. THE ILLNESS ALONE IS DEVASTATING ENOUGH FOR THE CHILD AND THE FAMILY. WE CANNOT STOP THE ILLNESS. BUT WE CAN HELP BY INSURANCE FOR HELATH CARE. I LOOK FORWARD TO HEARING THE THOUGHTS OF OUR EXPERTS TODAY AND TO WORKING ON THIS PROBLEM.

I ALSO WISH TO TAKE A MOMENT FOR A POINT OF PERSONAL PRIVILEGE. I WANT TO BRING TO THE AWARENESS OF THE MEMBERS OF THESE COMMITTEES A SITUATION INVOLVING CHILDREN WITH CANCER AND OTHER CHRONIC ILLNESSES WHO ARE PATIENTS AT THE NATIONAL INSTITUTES OF HEALTH. NIH IS RESPONSIBLE, OF COURSE, FOR TREATING PATIENTS FROM ALL OVER THE COUNTRY. THESE PATIENTS SERVE US ALL. BECAUSE THEY ARE WILLING TO UNDERGO EXPERIMENTAL TREATMENTS, WE ARE COMING CLOSER TO CURES FOR SOME OF THESE MAJOR ILLNESSES.

RIGHT NOW, THERE ARE OVER 40 CHILDREN AT NIH. THEY COME FROM ALL OVER THE COUNTRY AND ARE OFTEN COMPLETELY REMOVED FROM THEIR BROTHERS, SISTERS, GRANDPARENTS, FRIENDS. AT A PARTICULARLY LONELY AND DIFFICULT TIME, THEY HAVE VOLUNTEERED TO GO AWAY FROM HOME SO THAT WE CAN BENEFIT AND SO THEY CAN HOPE THAT MAYBE THE NEW TREATMENT CAN HELP.

ITS SCARY AND LONELY FOR THESE CHILDREN. AND IT IS SCARY AND LONELY FOR THE PARENT WHO ACCOMPANIES THEM. USUALLY, ONLY ONE PARENT CAN COME WITH THE CHILD. SOMETIMES, THERE IS ONLY ONE PARENT AND OTHER CHILDREN ARE LEFT AT HOME. THESE PARENTS, TOO, ARE TRYING TO MAINTAIN SOME SORT OF FAMILY LIFE. BOTH NEED THE SUPPORT OF THEIR FRIENDS AND THEIR FAMILIES.

UNTIL LAST SUMMER, WE PROVIDED ONE SMALL COMFORT TO THESE CHILDREN AND THESE PARENTS. NIH PROVIDED A PHONE AT THE END OF THE WARD. A CHILD OR THAT CHILD'S PARENT COULD USE THAT PHONE FREE OF CHARGE TO REACH OUT FOR SUPPORT, FOR HELP, AND TO KEEP IN TOUCH WITH OTHER FAMILY AND FRIENDS AT HOME. FOR SOME OF THE CHILDREN, THAT PHONE WAS ALL THAT WAS KEEPING THEM IN TOUCH WITH A "NORMAL" WORLD. FOR SOME CHILDREN AT HOME, IT WAS THE ONLY WAY THEY GOT TO KNOW THEIR SISTER OR BROTHER WAS OK, AND THAT MOM AND DAD STILL LOVED THEM.

BUT LAST SUMMER, NIH DECIDED THAT THE PHONE WAS COSTING TOO MUCH AND THAT PATIENTS COULD NOT USE THE PHONE BECAUSE THEY ARE NOT FEDERAL EMPLOYEES. INSTEAD, NIH INSTALLED A PAY PHONE. OR, THEY SAID, THE CHILD COULD USE THE PHONE FOR FREE IF A NURSE OR A SOCIAL WORKER SAYS IT IS NECESSARY AND THE CHILD DOESN'T HAVE THE MONEY.

I UNDERSTAND, AS WE ALL DO, THE CURRENT DEFICIT PROBLEMS. BUT THIS IS A HEARTLESS SOLUTION. THESE CHILDREN ARE AT NIH SO WE CAN BENEFIT FROM THE RESEARCH IN WHICH THEY PARTICIPATE. WE ASKED THEM TO SEPARATE FROM THEIR FAMILIES AND THEIR FRIENDS. THE LEAST WE CAN DO IS HELP THEM AND PROVIDE THE SIMPLE COMFORT OF A PHONE CALL. HAVE YOU EVER TRIED TO SEEK COMFORT OVER A PAY PHONE? IMAGINE YOURSELF AS A CHILD WHO IS SCARED, WHO IS SICK, AND AN OPERATOR SAYS "PLEASE DEPOSIT $1.50". OR IMAGINE YOURSELF HAVING TO INTERRUPT THE NURSE WHO IS HELPING YOUR VERY SICK ROOMMATE TO ASK IF SHE'LL SIGN A STATEMENT SO YOU CAN CALL YOUR DAD AND TELL HIM YOU'RE SCARED.

THIS SITUATION WAS BROUGHT TO MY ATTENTION BY MRS. CARMELA WALGREN, WIFE OF THE CONGRESSMAN FROM PENNSYLVANIA. CONGRESSMAN WALGREN AND OTHERS HAVE ASKED NIH TO PLEASE RECONSIDER THEIR DECISION AND ALLOW THESE CHILDREN THIS SMALL COMFORT. THEY DESERVE IT.

I HAVE WRITTEN TODAY TO DR. JAMES B. WYNGAARDEN, DIRECTOR OF NIH TO ASK HIM TO RECONSIDER AND TO KEEP ME INFORMED OF THE STATUS OF THIS SITUATION. I ASK EACH OF YOU ON THESE COMMITTEES TO DO THE SAME. I KNOW THAT WE CAN RESOLVE THIS SITUATION, AND GIVE IMMEDIATE HELP TO THESE 40 CHILDREN IN THIS VERY SMALL WAY.

MR CHAIRMEN, I AM ASKING FOR YOUR ASSISTANCE IN A VERY DOABLE SITUATION. RARELY, IN OUR TIME AS MEMBERS, CAN WE MAKE SUCH A HUGE DIFFERENCE IN THE LIVES OF PEOPLE WITH SUCH A SMALL STEP. BY WORKING WITH NIH TODAY, WE CAN HELP AT LEAST THESE 40 CHILDREN WHILE WE SEEK WAYS TO HELP ALL OF THE CHILDREN WITH CHRONIC AND CATASTROPHIC ILLNESSES. ONE NEVER KNOWS THE EXACT RELATIONSHIP BETWEEN MENTAL STATE AND STRESS AND RECOVERY OR REMISSION FROM CANCER. IF THESE PHONES CAN HELP ONE OF THESE 40 CHILDREN TO RECOVER OR EASE THE PAIN OF ONE THEY ARE WORTH IT. AND WE CAN DO SOMETHING ABOUT IT NOW.

AGAIN, THANK YOU FOR ALLOWING ME THIS POINT OF PERSONAL PRIVELEGE. AND THANK YOU TO OUR GUESTS TODAY. TOGETHER, WE WILL FIND WAYS TO HELP ALL CHILDREN, ALL PEOPLE WITH HEALTH CARE NEEDS.

THANK YOU.

Chairman PEPPER. Thank you very much, Ms. Oakar.

Now we have the Honorable Ike Skelton of Missouri, another very able and very interested and dedicated member of our Subcommittee on Health and Long-Term Care, the Honorable Ike Skelton.

STATEMENT OF REPRESENTATIVE IKE SKELTON

Mr. SKELTON. Thank you, Mr. Chairman.

My remarks are very brief because we do wish to hear from the panel. I merely wish to compliment both you and the gentleman from California, Mr. Miller.

Joint hearings are not all that common. When you have a joint hearing from the two subcommittees that we have today, you have a great deal of interest across the spectrum. I know that as a result of this, there will be a great deal of knowledge gained by the Congress, a great deal of impetus to move forward on the issue.

I compliment the witnessees on coming and sharing their thoughts and their time and their talents that they have offered in this cause.

I compliment them and particularly, Ms. Sullivan. Thank you, Mr. Chairman.

Chairman PEPPER. Thank you, Mr. Skelton.

Chairman MILLER. I'd like to introduce Dr. Roy Rowland who is a member of the Select Committee on Children, Youth, and Families and represents the State of Georgia.

STATEMENT OF REPRESENTATIVE J. ROY ROWLAND

Mr. ROWLAND. Thank you very much, Mr. Chairman, and may I congratulate both you and the Senator for holding this joint hearing on the health needs of critically ill children.

I appreciate this opportunity to learn more about the health related problems that confront the families of these children and to receive an update on the current status of public and private efforts to provide necessary medical services. As you know, the issue of catastrophic illness is one of the most pressing concerns in the 100th Congress and not surprisingly, numerous legislative proposals have been introduced. However, most of these proposals do not extend beyond the elderly in providing protection for catastrophic illnesses.

An illness of this kind is devastating, both financially and emotionally, no matter how old the victim is. However, when a child is faced with such an illness, the impact on the family may be different than when the victim is elderly. I think it is very important that both of these Committees, one that focuses on aging and the other that focuses on children and the families have joint hearings. It demonstrates a sensitivity to the fact that subtle differences in insurance needs for the young and the elderly may exist.

Although catastrophic coverage for the uninsured or under-insured has historically been the responsibility of State and local governments, the time, I believe, is right to explore what role the Federal Government may play in encouraging reasonable catastrophic protection for all who need it. I'm sure that when we leave here today, we will have a better understanding of what the needs are

for children and how we may best focus our energies on these needs.

I commend the people who are here today to provide testimony this morning and I look forward to joining in efforts to address the issue of catastrophic insurance coverage for all Americans.

Thank you very much, Mr. Chairman.

Chairman PEPPER. Thank you very much, Mr. Rowland.

At this time, if there are no objections, I would like to submit the prepared statement of Congressman George C. Wortley for the hearing record. Hearing no objections, so ordered.

[The prepared statement of Representative George C. Wortley follows:]

PREPARED STATEMENT OF REPRESENTATIVE GEORGE C. WORTLEY

Mr. Chairman, I commend you for holding this special joint hearing. I find this hearing especially important as I have the honor of serving on both select committees.

Oftentimes, when we think of catastrophic health care, we think exclusively of the elderly population. We fail to address the rest of the population who are also at risk for catastrophic illness. Thousands of children each year require transplants, corrective surgery, or an operation following an accident. Indeed, the spectrum is much larger than most of us have been focusing upon.

So many families are uninsured or under-insured, and it is a tremendous financial drain on a couple just beginning their family. The impact of a child's catastrophic illness upon a family is immeasurable. Beyond the financial considerations are the other children in the family--the emotional drain on the parents and the possibility that the other children may feel deprived of their parents love and attention because so much of the parents time must be devoted to the chid who is ill.

All of these aspects must be taken into consideration when discussing catastrophic illness. We must widen the scope of our consideration to include the younger population and the impact upon the entire family.

Chairman PEPPER. I'd like to introduce the gentleman standing over here to the right who represents the National Foundation for Hospice and Home Care and was the one who put together a very fine film that we saw a few moments ago in another room, Mr. Bill Halamandaris.

Now, the lady who narrated that film so beautifully and who is doing such a magnificent job in this critical area of care for the children is the lovely lady, a distinguished and beautiful actress, Ms. Susan Sullivan.

PANEL ONE—YOUNGER AMERICANS WITH CHRONIC HEALTH PROBLEMS: CONSISTING OF SUSAN SULLIVAN, ACTRESS, LOS ANGELES, CA, AND SPOKESPERSON FOR NATIONAL FOUNDATION FOR HOME CARE, WASHINGTON, DC; RANDY KRAMER, MIAMI, FL; ANGIE BACHSCHMIDT, WASHINGTON, DC, ON BEHALF OF HER SON ROBERT, AGE 4; TRACY SUTTON, PHOENIX, AZ, ON BEHALF OF HER SON ALEX, AGE 3; SANDY RECKEWEG, WALDORF, MD, ON BEHALF OF HER SON JEFF, AGE 5; JOE MILLER, LOS ANGELES, CA; STEVEN BROWN, BETHESDA, MD; DIANE FLEMING, BETHESDA, MD; DEBORAH RUSSELL, KALAMAZOO, MI, ON BEHALF OF HER SON DANIEL; AND REV. ROBERT K. MASSIE, JR., BOSTON, MA

STATEMENT OF SUSAN SULLIVAN

Ms. SULLIVAN. Thank you, thank you Senator Pepper.

Mr. Chairman, members of the committee, my name is Susan Sullivan. I'm here as a member of the Board of Trustees and national spokesperson for the Foundation for Hospice and Home Care.

I am sorry that everybody did not see this film and I hope you will get a chance to see it another time.

I have an official statement that I'm not going to bore you with by reading it to you. I'd like to submit it for the record.

Chairman PEPPER. Without objection, it will be received.

Ms. SULLIVAN. I think that these children and these parents will speak far more eloquently on this issue than I can.

I would like to make one personal observation, if I may, that really has nothing to do with the foundation's report.

It seems to me and I suppose it's partially my observation as an actress, as I look around at these children and at these parents, that we all have such a deep longing to be taken care of and a hope that in this high tech society of ours, somebody is going to come up with a solution to all of our greatest fears, those of illness, those of dying, and that these problems can be solved. I think there is a great danger in this hope because I think what happens is that we abdicate our responsibility and when we abdicate our responsibility, we lose our personal power.

When my father was dying, he was in the hospital. He had cancer. He was ready to come home. This is probably a terrible thing to say, but we did not want him to come home. He did not want to come home. We were terrified. We were terrified that we wouldn't be able to take care of him. My father was a wonderful man, but difficult in the best of times and certainly, these were not the best of times.

He did come home. We did take care of him. It's always hard for me to say this because it sounds strange. It was probably one of the most powerful, one of the most important times in the life of not only my father, but of my family. We came together in a way that you can only come together around great issues, around life and death issues, around this kind of illness where poeople find out who they are. You either rise up and become the best of yourself or you don't. These families have similar careers.

All these parents want is the opportunity to take care of their own. All they want is the opportunity to take on their responsibilities.

How can we not help them to do this?

I think technology is a very poor substitute for humanity. As we become even more sophisticated in this society, we are going to have to deal with the aging process. We are all going to have to learn how to take care of our own. We have here before you leaders and great examples of that. So I ask this committee, as you deal with the catastrophic health insurance problems, please don't forget these children. I think the only greater catastrophe would be if we didn't help them.

Thank you.

Chairman PEPPER. Thank you very much, Ms. Sullivan, for all that you have contributed to this meaningful subject.

[The prepared statement of Susan Sullivan follows:]

PREPARED STATEMENT OF SUSAN SULLIVAN, MEMBER, BOARD OF TRUSTEES; AND SPOKESPERSON FOR THE FOUNDATION FOR HOSPICE AND HOMECARE

Mr. Chairman, Members of the Committee, my name is Susan Sullivan. I am here today as a member of the Board of Trustees and spokesperson for the Foundation for Hospice and Homecare.

I have been involved with hospice since the death of my father. He had cancer and died at home. I can't tell you how much it meant to have him home at that time.

It was one of the most powerful experiences in the life of my family. We lived the last part of his life together. That simply would not have been possible if we had left him in a hospital.

I became involved with chronically ill children two years ago. At that time, I had a chance to meet some of these children and their families. I found their experiences were strangely similar to my own.

Chronic conditions and critical illness give you a heightened sense of what life is about. My father was at the end of his life. These children are just beginning theirs. But we share a concern for the quality of life. We all want to keep our families together.

Shortly after meeting these families, I was asked to represent the Foundation before a Senate Committee interested in the exploring home care for chronically ill children. Although I was happy to oblige the Committee, I remember wondering why a hearing was necessary.

The issue seemed so clear and the answer so obvious, I wondered why it had to be discussed.

We all know children belong at home. This instinctive reaction is supported by years of research and countless studies which document the importance of family support to a child's development.

We all know about the progress of medical technology. The manifestation of that technology is before you. The same technology that keeps many of these children alive has been minaturized to the point where it is portable. This has made it possible to safely care for most techonolgy-dependent children at home.

We also know that home care is almost always cost-effective. On the average, we found the cost of caring for these children at home is about one fourth of the cost of supporting them in an institution.

So, if it is better for the child and better for the family; if the technology is here; and it is safe and cost-effective to bring these children home - why isn't that happening?

Given our society's tradition of concern for the young, what about these children makes them so different that we neglect their needs?

Why, as you will hear, do we make families move from state to state and even give up their children before we will provide the assistance they need?

Why will the government and most insurance companies spend literally millions of dollars a year to support these children in institutions but not a fraction of that to send them home?

Over the last two years, the Foundation's staff has travelled across this country to determine the nature and prevalence of this problem. We have talked to dozens of families, doctors, nurses and other health professionals. We have interviewed representatives of insurance companies and we have talked with Federal, state and local policy makers. We have produced the documentary you have just seen and the report to be discussed by the next panel.

Our conclusion is that there is one overriding reason this problem continues. All of our health programs are structured to deal with acute illness. These children, like the growing number of seniors on the other side of life, have chronic health conditions.

What they need is long-term care. What they need is a coordinated national program that is flexible enough to adapt to the uniqueness of each situation and comprehensive enough to provide the assistance necessary.

Mr. Chairman, I know you and your colleagues deal with a dozens of difficult issues every day. Day in and day out you must decide questions of national security and economic importance.

You must worry about arms control and the environment, balancing the budget and the deficit, farm policy and foreign affairs. All of these and others are complicated issues. They present options that seem a thousand shades of grey and require neat judgment.

This isn't one of them. Rarely will you have a chance to do something so obviously right and so clearly necessary.

Rarely will you have a chance to do something that can so significantly improve the lives of your constituents and the strength of our society.

There is no down side to this issue. There are no cost over-runs. You don't have to worry about the adverse reaction of interest groups or the enemies you might make.

This is an issue that has been endorsed by Republicans and Democrats, liberals and conservatives alike. The issue here is as basic as humanity and as fundamental as compassion.

In short, this is chance to be on the side of the angels. All these children need is a program that allows them to lead something resembling a normal a life.

As you continue your discussions of catastrophic health insurance, I ask you to remember these children. There is no health need larger than theirs. In fact, the only greater catastrophy I can imagine is if we do nothing to help them.

Thank you.

Chairman MILLER. Next we will hear from Randy Kramer from Miami.

STATEMENT OF RANDY KRAMER

Ms. KRAMER. By looking at me you may say to yourselves what's wrong with her, she looks OK. Well, things are not as great as they appear. You are going to have to hear about my disease because you can't see it.

I have a disease called cystic fibrosis. This disease causes thick mucus to collect in my lungs, making it difficult for me to breathe. To a normal person, it may feel like having the flu. To treat CF I take aerosols and medication and somebody hits me for an hour twice a day to bring up the congestion to make it easier for me to breathe. It's degrading for me to have to live my life around somebody to keep me alive, but I fight back and I do everything I can in my power to keep myself going.

That is why I'm here today. I'm up against bureaucracy, besides having to deal with the symptoms of my disease. I am 27 and on the medicare program. I have been eligible for medicare since I was 22. Medicare pays my doctor bills and my hospital bills, except for the deductible. I see the doctor once a month and am hospitalized at least three times a year for a 2-week stay. In addition, I have to go to the hospital twice a day for therapy. I used to have my therapy at home until I reached the limit on my private policy. But I have to have it in the hospital now. The medicare policy says that in order to receive home care, I must be homebound and even when I'm homebound, Medicare will only pay for physical therapy or skilled nursing up to $500 per year. They do not pay for respiratory therapists, who are qualified and trained to take care of people with problems like mine, but they do pay for outpatient treatment in the hospital.

I use the outpatient department at Baptist and Doctors Hospital for my treatments, costing $350 per day.

The cost for the same treatment at home is $50 a day. The government has been billed—are you ready for this amount—$90,000 for my outpatient treatment since last March.

I did some research on my own and found that in the United States, there are approximately 800 patients with cystic fibrosis who receive treatments at the hospital, costing an average of $125 per treatment. These patients are on Medicare and it is costing the government approximately $200,000 per day and $6 million per month.

Now, if these patients were to receive treatment in the privacy of their own home, the average cost would be $25 per treatment, saving the government $4.8 million per month.

Would you believe Medicare has closed their eyes to this savings? Kathy Gardner, who was put on my case last year, and myself received a letter from Dr. Bowen stating it would require a specific legislative change to have respiratory treatments covered under the Medicare home health benefit when serviced by a respiratory therapist. The punchline is, Medicare decided to take two of my outpatient therapy bills totalling $7,000 and reject them because these services were the type that can be done at home. In addition,

I used to go to the physical therapy department and exercise with the mist treatment and oxygen. This was to try and maintain my lungs and try to improve their capacity. After 6 months of treatment, I was recently notified that Medicare will not pay because these treatments are not medically necessary.

The bills amount to $6,000. Whoever denied this should live in my body and see how it feels and tell me it is not medically necessary. More important than the financial savings is that personal freedom has been taken away from my life. It's bad enough I have to take treatments every day of my life, let alone plan the day around going back and forth to the hospital. It takes me 3 hours to get one treatment. It takes almost a whole day because I take 6 hours for two treatments. This makes me feel even worse. I get tired, I get sick. I pick up more viruses because I'm exposed to them in the hospital. I was hospitalized five times last year and it's not my choice to have this done every day. I have to do it in order to stay alive.

A lot of people who have health problems say oh, I'll take care of myself tomorrow. I can't afford to take these chances. The quality of my health—my life is very important to me because I don't have the quantity. There's no cure for CF. Treatment is directed toward other illnesses like asthma, emphysema, chronic bronchitis. There's nothing in the book that gives a specific treatment for cystic fibrosis.

Twenty years ago, they were offering the same treatment that they are today. With all this new technology, it seems they would have found a better treatment or more of a medical help. CF was never noticed as a significant problem. That's because they never saw anyone live long enough. All of them died at age 12. Some of us were lucky to stick around and I'm a part of the new generation. I am here today because I'm living and I'm a prisoner of my own life right now. I can't get help and I wish you would please help me escape because I can't get through all this red tape and the President's catastrophic plan would not help me at all.

It's up to you and Congress to help me and everybody else like me.

Thank you.

Chairman MILLER. Thank you, Randy.

[The prepared statement of Randy Kramer follows:]

PREPARED STATEMENT OF RANDY KRAMER, MIAMI, FL

Good morning. My name is Randy Kramer. I'm 25 years old and I live in Miami. Some of you may be looking at me and thinking, she appears to be in perfect health -- why is she here? The fact is I have cystic fibrosis, a disease which causes thick mucus to collect in my lungs, making it feel like there's a pillow over my face when I try to breathe. Years ago, this debilitating illness would have required confinement to a hospital. Now, though, I can fight back, devoting my life to taking care of my health. Since I first learned I had CF, I have become well educated in lung disease and the treatments available. For five hours each day I exercise and take two respiratory treatments -- in fact, I'll have one as soon as I leave this hearing. These treatments are not a cure-all but a means of survival. They provide a few hours of relief of not being conscious of every breath I take. Having cystic fibrosis has also taught me about the baffling bureaucracy of the U.S. health care system. I'd like to tell you a little about my experience in that area. I have been eligible for Medicare since I was 22. Medicare pays my doctor bills and hospital bills except for the deductible, which is now $520. I have to see the doctor once a month and I am hospitalized on an average of three to four times a year. Each time I am hospitalized, I stay a minimum of two weeks. In addition, I have to go to the hospital twice a day for therapy. I used to have my therapy at home until I reached the $50,000 limit on my Aetna insurance policy. Medicare won't let me have therapy at home because I don't meet their criterion of being homebound. Even when I am homebound, Medicare will only pay for a physical therapist or a skilled nurse. They do not pay for the respiratory therapists who are qualified and trained. Because of these quirks in the benefit structure, I am forced to use the outpatient department of the Baptist Hospital for my treatment. The cost of these treatments is roughly $350 a day, but the cost of the same treatment at home is about $50 a day. The government could save a lot of money by letting me get therapy at home. It would be better for me because every time I go to the hospital, I am exposed to sickness that could cause readmission to the hospital. I am burning up my Social Security money on transportation, and the trips back and forth also mean wear and tear on my body. As you know, there is traffic in the morning and getting up at 6 o'clock in the morning is difficult for me. I have a new insurance policy which is supposed to cover 80 percent of what Medicare doesn't pay. I thought it sounded promising, but it has a $1,000 deductible and it doesn't cover home care. Another dead end. I have tried everything I can think of to try to get coverage for my treatments at home. I wrote Congressman Pepper, who then wrote a letter to Secretary Bowen at Health and Human Services. The reply was negative. Mr. Don Newman, Under Secretary of HHS, wrote that, although there are some parts of the Medicare law in which there is flexibility, this was not one of them. I am not "homebound" and so the home care benefit is denied to me. Period. I've also tried persuading my insurance company to cover home care, but without success. When I get sick, I need help, and I need help from getting sick. I don't think it should be such a struggle to get the high-quality health care I need in the best possible setting. Limitations on the provision of health care are hurting rather than helping. With all the hard decisions legislators have to make in light of current budgetary constraints, expanding health care options outside the hospital would save money, and improve the health of many. I should tell you that there was another development in my story just last week. I got a notice from Medicare that they would not honor over $7500 in bills for my therapy, even though these are expenses I know they've covered for me in the past. And what was the reason cited? In a classic "catch 22" response, the notice said that Medicare couldn't pay for these services in the hospital because they could be provided in the home. Can you believe it?

I am a fighter and I intend to keep fighting this illogical situation. I hope those of you in Congress will pay close attention to the stories presented today and work to enact some kind of policy to help those of us with chronic illnesses. The President's catastrophic plan would not help me at all. It's up to those of you in the Congress to help us. In my case and in many others, the home care option would save the government money -- about $4.5 million per month, according to my calculations, for cystic fibrosis patients alone. Thank you.

Chairman PEPPER. We're going to question the witnesses later, but I can't refrain from saying that what Ms. Kramer just told us not only indicates the callousness, but the ridiculousness of the program that we follow today. I'm sure that our committee here jointly is going to recommend a new definition of homebound, which will permit you to get the home care that you are entitled to receive, Randy.

The next witness will be Mr. Robert Bachschmidt, age 4 of Washington. He suffers from muscular dystrophy. He's accompanied by his mother, Mrs. Angie Bachschmidt and we'll be glad to hear from you, Mrs. Bachschmidt.

STATEMENT OF ANGIE BACHSCHMIDT

Mrs. BACHSCHMIDT. Good morning.

I am Angie Bachschmidt and I'm from Washington, DC. I am here to tell you about my youngest son, Robert. He's age 4 and he suffers from muscular dystrophy. He has a severe form of muscular dystrophy that is congenital and has kept him in and out of the hospital intensive care units for 2 years of his life. While in the hospital, he was placed on a ventilator to save his life. Because we realized that Robert would probably need ventilator assistance for the rest of his life, and we so desperately wanted him home with us, his father and I approached the staff of Children's Hospital of the King's Daughters in Norfolk, Virginia, where we were living at the time about the feasibility of caring for Robert at home. We were informed that neither the hospital nor the State of Virginia had the necessary resources to properly care for Robert at home. In desperation, we approached other hospitals outside the area. Philadelphia Children's Hospital turned us away; so did Bethesda Naval Hospital. Finally, in April, 1984, Children's Hospital National Medical Center in Washington, D.C. accepted Robert as a child to receive home care.

My husband is a first-class engineman in the Navy and through the Navy, we are covered by CHAMPUS health insurance. When Robert was accepted at Children's Hospital, the Navy graciously granted us a humanitarian transfer to Washington, DC. At the time of our transfer, CHAMPUS approved Robert's home care and agreed to pay for his medical costs. Then we got unsettling news. CHAMPUS would pay a maximum of $1,000 per month for home care expenses. This amount would not even cover the rental costs of Robert's equipment, not to mention needed supplies, nursing care and the other resources necessary to ensure quality care at home. Despite our attempts to reason with them, CHAMPUS refused to cover our expenses. Robert remained at Children's Hospital, where his expenses for 18 months of hospitalization totalled $865,800. Home care for this same period of time would have been approximately $90,000—nearly one-tenth of the cost of hospitalization.

In an unsuccessful attempt to get access to home care, our family had moved from Virginia to Maryland, where we heard the chances were better. Again, in hopes of having Robert home with the family, we had to move to Washington, DC. We were told that

with special permission, medicaid would cover expenses for home nursing. Finally, in January of 1985, Robert came home.

Robert has received home nursing care for 2 years. CHAMPUS pays for most of Robert's supplies such as the respirator and catheters, as well as equipment needed to clear his lungs. Even so, many of Robert's needs go unmet. He does not receive any physical therapy, occupational therapy or speech therapy because these are not reimbursable by CHAMPUS or medicaid. I am responsible for the costs such as increased utility bills, transportation, and other additional costs. I wish my family could get assistance in dealing with the stress of caring for technology-dependent children, either in the form of respite care or social work and counseling. Unfortunately, such resources are not available. I am left alone to pull all the necessary resources together and figure out how to pay for them.

Saving a child with modern technology is a blessing. Being able to keep that child at home is a blessing too, but unless there is some guarantee of provision of comprehensive services, quality home care is impossible. Being at home with his family has made a wonderful difference for Robert. You wouldn't believe it's the same kid who was in the hospital. They say children who have been trached can't talk, but he talks. He laughs and smiles and will kiss you.

I think families should have the right to care for their children at home, regardless of the State they live in and who's going to pay the bills. Having a chronically ill child is difficult. At least families should be given the help they need.

Thank you.

Chairman PEPPER. Thank you very much, Mrs. Bachschmidt.

Chairman MILLER. Next, we will hear from Tracy Sutton, the father of Alex Sutton, of Phoenix, Arizona, who suffers from Tay-Sachs disease.

Mrs. SUTTON. All right, we have a little change, his mom's going to speak.

Chairman MILLER. You changed the order and mom's going to talk here?

STATEMENT OF TRACY SUTTON

Mrs. SUTTON. Good morning. My name is Tracy Sutton and I'm Alex's mom. Alex will be 3 next month. I'm here to tell you about him. He suffers from Tay-Sachs. It's a degenerative and terminal disease which causes the breakdown of the nervous system. Alex developed as a normal child until about the age of seven months. At that time we noticed that he was not learning new things. That's when we became anxious to find out exactly what was going on. The doctors told us what they wanted to do was wait until Alex was a year old before they did any analysis because typically children develop at different rates. We felt that there was definitely something wrong. We took him to a child development specialist and she suspected he was going to be severely retarded. We didn't know why. We decided to go through further testing and that's when we came up with the knowledge that Alex had Tay-Sachs Disease, a genetic disorder.

The doctors first said that Alex would live approximately 3 to 5 years. Now they said it's back to 3 to 4 years. They warned us that Alex's development would reverse and he would go back to being like a baby, which is pretty much where he is now. He can't do much of anything. He's blind. He can't laugh or cry or even move. He is in constant need of respiratory treatment to prevent pneumonia. His feedings are given by means of a G-tube. He has a series of medications he has to take to control his epileptic seizures, which sometimes last 25 to 30 minutes. It's very difficult to get the right combinations of medications to keep his seizures under control. His medications also have serious side effects such as internal bleeding and liver toxicity.

In the State of Arizona, there are no financial programs established to aid people with this type of catastrophic illness. It's hard for me to believe that there is no program set up for children in Alex's situation. The only options open to us would have been to have the insurance company allow him to stay in the hospital on a full-time basis, which they didn't want to do, or make Alex a ward of the State, in which case we would have to give him up. We don't want to do that. Alex is our baby. We want him at home with us.

Fortunately, we were able to persuade our insurance company to cover home health care. This was not an easy task, but with the assistance of numerous doctors, they finally conceded it is the best kind of care for Alex and it is also a better bargain for the insurance company than hospitalization. Tony had Blue Cross-Blue Shield which would cover 80 percent of total costs. In our case, that's 80 percent of $200 to $250,000 a year, so the 20 percent that we would cover out of pocket, would still have been an awful lot and in fact, there is even a maximum on what Blue Cross can pay for catastrophic coverage. We are more fortunate than most because I work for a large hospital system and have excellent insurance. If I didn't have that, I don't know what we would do.

Obviously, there is a great need not only on the State level but at the national level. The new Reagan plan wouldn't do anything for children, so that's not the solution. There needs to be an awareness of the catastrophic health care needs of children. Policies must be created to establish precedents, so that when someone is faced with a situation like this, they know where to turn for assistance. A catastrophic illness such as Tay-Sachs is emotionally straining and the victims should be assisted with their financial burdens.

Thank you.

Chairman PEPPER. Thank you very much.

Now, the next witness is Jeff Reckeweg. He's age 5 from Waldorf, Maryland. He has hyperventilation syndrome, a respiratory disorder. He's accompanied by his mother, Ms. Sandy Reckeweg, and we would be pleased to hear you.

STATEMENT OF SANDY RECKEWEG

Ms. RECKEWEG. Good morning. My name is Sandy Reckeweg and I live in Waldorf, Maryland. I would like to introduce you to my 5½-year-old son Jeffrey.

Jeff and many others like him are the reason we are all here today. When Jeff was 14 days old, he stopped breathing for the first time. This was the beginning of our son's numerous and perplexing medical problems. Our son suffers from a rare and little understood disorder called hyperventilation syndrome. This is a combined respiratory and brainstem disorder in which Jeff does not appropriately respond to CO_2 in his bloodstream. As a result, during sleep and even at times during the day, Jeff's breathing becomes dangerously shallow. This can lead to chronic respiratory failure, heart failure and death if the child is not properly ventilated. In short, our son's life depends on the miracles of today's technology.

Jeffrey spent the first 18 months of his life in a pediatric ICU. Those were difficult times for our entire family, especially for our older son, who was only 3 years old when Jeffrey was born.

When the decision was made to trach and ventilate Jeff during sleep, we all talked about home care as an option. After 18 long months, we were more than ready to bring our son home and hopefully enjoy some sort of family life. I was absolutely obsessed with getting our son home. The hospital was raising our child. When a child is in the hospital for a long period of time, one begins to lose perspective that he is your child. It almost felt like our child belonged to the hospital. His doctor would not release him without skilled nursing care. The biggest obstacle was money. Jeff's health insurance was used up by the time he was 9 months old. We were in a real dilemma. We were told our son would never again have health insurance. Imagine being nine months old and being uninsurable. After contacting the press and much, much persistance, Crippled Children's Services of Maryland agreed to pay for Jeff's home care on a temporary basis.

My husband and I have gone through many emotional ups and downs the last 5½ years. We've experienced fear of losing our son, anguish over not being able to bring our son home due to lack of money, and despair over huge hospital bills due to not being able to qualify for any assistance, because my husband made too much money, even though Jeff had no insurance. To this day, we still owe Children's Hospital $800,000.

We felt joy at Jeff's survival and at finally being able to bring him home and pride at the wonderful success his home care has been. We are very blessed to now be covered by the State of Maryland model waiver program. Without it, Jeff might very well have grown up in a hospital intensive care unit. Up until his discharge at age 18 months, Jeff had never seen it rain, seen a flower or experienced the thrill of coming down his stairs on Christmas morning.

It is difficult to comprehend what Jeff's life would have been growing up in a hospital. Jeff now attends kindergarten in our area school, rides his big wheel with his friends, eats popsicles, learned to ski this winter and is even signed up to play soccer next month. Quite a fun and high-quality life for a child who depends on technology for survival. We are fortunate to have such a State program. However, there are others in similar circumstances who do not have the same. There are only a handful of States with such a program.

Our population of children is surviving illnesses which 10 years ago they would never have survived. People have to understand, technology is often keeping these children alive. However, our society really does not know what to do with these children once they have survived. I feel every child deserves the right to grow up with a loving family. I recently asked Jeff's 8-year-old brother what he liked best about having his brother home. He replied, "I love the things we do together". He also replied to me, "I hate when Jeff goes into the hospital. I am so lonely without him". They are each other's best friends.

The average person takes something so simple as growing up with a sibling for granted. These children have so much potential. Let's make home care an available option for all chronically ill people, young and old.

Thank you.

[The prepared statement of Sandy Reckeweg follows:]

PREPARED STATEMENT OF SANDY RECKEWEG, WALDORF, MD., ON BEHALF OF HER SON JEFFREY

Good morning. My name is Sandy Reckeweg and I'm here to tell you about by son Jeffrey, who's five years old. When Jeff was about 14 days old, he stopped breathing for the first time. I was holding him in my arms in our bed and noticed he wasn't breathing. In a panic, I screamed at my husband and after trying several things desparately we finally started Jeffrey breathing again.

Jeffrey got progressively worse instead of getting better and after an initial misdiagnosis of sleep apnea, they tested him again and gave us the diagnosis of Ondines -- a syndrome in which Jeffrey's brain fails to tell his body to breath at night during sleep. This can happen at any time.

Jeffrey was in the hospital for about 18 months. He was in for a year and home for about five weeks. Then he would be in the hospital for three weeks; he'd be home for a day; he would have respiratory arrest; he would have to go back to the hospital; he would spend another month; he would come home for two days; he would arrest again; he would be back in the hospital. So finally, we just decided to keep him in the hospital.

Then the doctors decided to put Jeff on a respirator full time whenever he sleeps. This would allow him to stay at home. And after spending that much time in the hospital, I was very ready for Jeffrey to be at home. When you have a child who's in the hospital for that long, especially in intesive care or a critical care unit, you sort of lose the perspective that he is your child. You can't even give him a hug in private, say. You have to always feel that, you know, the doors are open. I wanted to raise my own son.

The biggest problem was and is MONEY. We had a health insurance policy with a limited lifetime coverage of $100,000. That was completely exhausted no more than 9 months after Jeffrey was born. We were told by different insurance companies that he could never get insurance with his pre-existing condition. We even applied for Medicaid, but were turned downed because the State said we had too much money. The result? We are now in debt for about $800,000. It costs over $600,000 a year for the health care Jeffrey needs to stay alive in a hospital!

I wrote letters and called everyone I could think of. I was absolutely obsessed with getting Jeff home. Then, we got lucky. The Crippled Children's Services of Maryland agreed to pay for home care for Jeff. It costs about $14,000 a month -- about one fourth the cost of care in the hospital. This includes 16 hour a day nursing care, the rental of his respirator, his oxygen, all of his equipment and medical bills.

There's a big difference with Jeff at home. He's brigher. He's happier. It's really hard to explain how much he's grown. He came home a docile little kid without any spunk at all. He had never been outside. He'd never seen a cloud; he'd never seen it rain; he never seen it snow. So when we got him home, the first thing we did was to take him out and who him all the nature of things people take for granted that these kids can't experience when they're growing up with four walls of an intensive care unit. Now Jeff has a wonderful life and there are very few limits on what he can do.

However, the support from Crippled Childrens could end at any time. If that would happen I don't know what we'd do. I do know that we can't afford the cost of his care. People have to understand, technology keeps many kids alive. But nobody seems to know what to do with them once they are alive, and I really think society owes them the right to be at home getting the health care they need. We need a catastrophic health care program which would provide this -- every day that goes by without it, people suffer. Thank you.

Chairman PEPPER. Mrs. Reckeweg, I just want to comment so that the record will show what a lively handsome little fellow Jeff is.

Ms. RECKEWEG. Thank you.

Chairman PEPPER. He's writing now with a pencil and smiling and enjoying, apparently, what's going on here—being in the spotlight. That little child might not be alive if it had not been for what you told us it was possible for you to have been able to give him.

Ms. RECKEWEG. You better believe it.

Thank you very much.

Chairman PEPPER. There's a lot of illness today that we don't have the answer for.

My wife passed away with cancer. I resorted to every source that I knew of to try to find some way to save her. There wasn't any.

But we do have technologies now that will save the lives of many and make it possible for them to enjoy relative health. Surely, surely we must provide some way to make that technology available to those who need it.

Chairman MILLER. Thank you.

Next we'll hear from Joe Miller, who's from Los Angeles.

STATEMENT OF JOE MILLER

Mr. JOE MILLER. Good morning. I'm 18 years old and I live in Los Angeles, California.

In 1985, about 2 years ago, I was at my friend's house. It was the day before our finals at school, our mid-semester finals. We were leaving, getting ready to go study. I was riding my 10 speed and I was going up the street. All of a sudden, my front tire flipped off and I landed on my head and I broke my neck.

I spent the next 7 months in the hospital and I was pretty much paralyzed from about the nipple line of the chest down. One day when I was in the ICU unit, I asked the doctor if I was ever going to be able to walk again and function normally. He told me no, that I wouldn't be able to, but that anything's possible, you know, since they don't know too much about the spinal cord. But he told me that he assumed that I would never be able to walk again.

It was rough for the first few months but I have slowly been adjusting every day of my life now. The biggest problem is that I need nursing care at home, but since the government will not pay for it my mom has been having to take care of me and that means she is unable to work. We have trouble, you know, making ends meet from month to month, week to week, with rent, pills, et cetera.

We have filed with the Social Security and homemaker chore program they have in California to get help. We finally were granted the homemaker service and we found they would pay $3.72 an hour for the 7.5 hours of care a day they thought I needed. With the help of my social worker, we were able to prove I needed more than 7.5 hours of care. However, it's impossible to hire anyone for $3.72 an hour. No one will work for that, so we've been put in a position of going on welfare.

I was granted Social Security, but because my older sister worked, they considered her income as part of the household's.

Therefore, I was allowed only $38 a month Social Security. When my sister moved out, they increased my SSI to $103. We face the same problem with my younger sister, Kathy, who is 15. She wants to get a job to help, but if she brings in additional family income, they'll cut my SSI benefits, more than likely.

These kinds of policies force people to do desperate things. I had a friend who was in the hospital—my roommate for a while—and then he left the hospital. He had nursing for a while and then they cut it. He was pretty depressed about his situation. When they cut his nursing, he contemplated and tried to commit suicide. I guess he felt that it wasn't worth putting people through the problems that they would have to face not being able to be taken care of, whatever, and having his parents take care of him.

It seems to me almost like someone is trying to make things difficult for us. They are telling us that we can't justify our needs. It's crazy because a week's cost of keeping me institutionalized is more than the cost of caring for me at home for 10 months. Bills for my stay in the hospital are coming in at $18,000 a month. On the other hand, medical supplies and everything run about $500 to $1,000 a month for my care at home. So far most of my bills have been paid by my parents' insurance policies. Between the two of those they've pretty much covered it, but because my mother takes care of me now, she can no longer work. Her coverage is ending and my father's insurance will only continue for a year.

After that, I don't know what will happen. I do know that the bills are very, very horrendous and unless some changes are made under the government policy, I'm going to be facing a lot of these problems and challenges for the rest of my life.

Thank you very much.

Chairman PEPPER. Thank you, Joe. The next is Steven Brown, age 22, from Bethesda, Maryland. He has Duchenne's muscular dystrophy. He's accompanied by his mother, and Steven, we'd be pleased to hear from you.

STATEMENT OF STEVEN BROWN

Mr. BROWN. My name is Steven Brown. You see my situation. I doubt that anybody would agree with me, but if it happened to you and you could not be at home in the security of your family to live your life normally, comfortably, with dignity and respect for the human condition for society as we know it.

Thank you very much.

[The prepared statement of Steven Brown follows:]

PREPARED STATEMENT OF STEVEN BROWN, BETHESDA, MD

My name is Steven Brown. I am 22 years old and have Duchenne's musculas dystrophy, a disease that gradually weakens the body's muscles.

In 1984, I was having trouble breathing and was close to death. I would have died if I had not been put on a ventilator and been fitted with a trach. I knew the surgery was risky but I decided to take the chance. I wanted to live. I was not ready to die.

I've been living at home with the ventilator for two and a half years. If I had to live in a hospital, I wouldn't want to live anymore. People on ventilators still have rights and I want to be with my family and friends. My life is worthwhile because I have my home, family, and friends. A hospital cannot be compared to a home.

I think that anyone who elects to live a life dependent on technology should also have the option of living at home. Our public policies should not prevent anyone

from receiving the care he or she needs at home. Please help make sure this is possible. Thank you.

Chairman PEPPER. Thank you Steven for your excellent statement.

Chairman MILLER. Next we'll hear from Ms. Fleming.

STATEMENT OF DIANE FLEMING

Ms. FLEMING. I am Diane Fleming. I am married and the mother of three children, two of whom are handicapped.

Steven is here with me today. He is of Korean American descent and was adopted when he was three years old. He has Duchenne type muscular dystrophy.

Chairman Pepper and Chairman Miller and members of this committee, I speak to you today after 19 years of caring for and loving a remarkable young man, my son Steven. We have had the support of the Muscular Dystrophy Association, Maryland Medicaid and last, but not least, our HMO Group Health Association. We have had home care nursing for 2⅓ years.

I know Steven's indomitable spirit and his stubborn will to live really depend in large measure on his being a part of our family life.

Steven has muscular dystrophy, a progressive disease that slowly weakens the body's muscles. Until the age of 19, Steven was able to breathe on his own, but in 1984, weighing less than 80 pounds, unable to swallow, with heart and respiratory failure, Steven decided to opt for life. The doctors warned about the risk of the necessary tracheostomy. They pontificated about the quality of life. One doctor told me, if he were my son, I would take him home to die, but Steven didn't listen. He chose instead, with characteristic stubbornness, to live. In effect, he said, "gentlemen, give me the quantity and I will take care of the quality." Steven is one of the oldest surviving victims of this type of muscular dystrophy. Against all odds, he has defied death, depression, despair and statistics.

Totally dependent on a respirator, a complete life support system, with 24-hour nursing care for his medical and personal needs, he still draws his exquisite pen and ink sketches, supervises the planning of an herb garden outside his window, sculpts tiny rosebuds in wax to be made into jewelry for his friends, raps with his friends, enjoys his music, goes to the movies with all his life-saving paraphernalia, laughs and loves and is very much in charge of his own universe.

At the time of Steven's decision to choose life support technology, the question of how we would pay for it was not an issue. Steven was covered by our high option health insurance policy with Group Health Association and they'd always covered his medical expenses.

After the surgery, the doctor gave Steven 3 months to live. Because the prognosis was so poor, Group Health agreed to make an exception to their policy and cover Steven's care at home. Through Group Health's Continuing Care Department, home care is provided in some short-term cases, but Steven is their only subscriber on a ventilator with home care nursing.

They agreed to pay for 24-hour nursing, the respirator and all the necessary respirator supplies which has amounted to about $15,585 per month. Maryland Medicaid covers his prescription medicines, his nasal gastric tubes, feeding bags and syringes. This amounts to close to $607 monthly.

Muscular Dystrophy has paid one-time equipment expenses, such as suction machines, a hospital bed and feeding pump of close to $2,000 and in the past 2 years, wheelchair repair and maintenance costs of $1,250. The total daily cost of the care he currently receives at home is $574 for daily care. Hospitalization would cost close to $1,500 per day.

The bottom line, in our case, is that if Steven had stayed in the hospital for this past 2⅓ years, it would have cost Group Health about 1.27 million. As it is the bills for his home care have amounted to $488,000. Home care then represents 38 percent of hospital care in Steven's case.

The resources which we have available in America are immense. Private organizations such as the Muscular Dystrophy Association in our case are ready, willing and able to help with patient care to the best of their ability. State and county programs, in some States, provide many health care services—counseling and respite care, to mention a few—but the availability of these services is not known by the average person in need of these services.

How does one know where to go for help when one doesn't even know that help exists? When catastrophic illness hits one's family, the emotional stress limits the functioning abilities of even the most articulate and informed person.

I cannot envision completely how to implement the needed Federal policy for home care, but I know it is essential that we have a Federal clearinghouse to disseminate information about available resources. That's a first step, but you must remember these services still do not meet the medical needs of those people who are catastrophically ill.

We have been very fortunate in having home care nursing for Steven. I urge you to make provisions to ensure that all people who need home care can receive it.

Thank you.

Chairman PEPPER. Thank you very much.

Chairman MILLER. Thank you.

[The prepared statement of Diane Fleming follows:]

STATEMENT OF DIANE FLEMING
BETHESDA, MARYLAND
March 23, 1987

My name is Diane Fleming. My son Steven has Duchenne's muscular dystrophy, and I want to tell you little about his case.

Until the age of 19, Steven was able to breathe on his own. Shortly thereafter, his condition deteriorated to the point of near death due to the progressive weakening of his breathing muscles.

You can understand my horror when his doctor told me, "If he were my son I would take him home to die." Steven told me he wasn't ready to die. He decided to risk surgery and live his life on a ventilator.

At the time of our decision in favor of life-supportive technology, I never gave a thought to how we'd pay for it. Steven was covered by Group Health Association, an HMO, and they'd always covered all his medical expenses. What I didn't know was that the policy did not cover home care. I also had no idea of the extent of Steven's medical and therapeutic needs at home.

After the surgery, the doctors gave Steven three months to live. Because the prognosis was so poor, Group Health agreed to make an exception to their policy and cover Steven's care at home. They agreed to pay for 24-hour nursing, the respirator, a battery, gloves, tubing, suction catheters, and respirator supplies, amounting to $15,608 per month. This in no way covered all of Steven's needs and I was left with the responsibility of finding additional resources. The Muscular Dystrophy Association (MDA) paid for Steven's wheelchair, feeding pump, bed, and suction machine ($7,500), and gives us $150 a month for equipment maintenance and special mattresses. Maryland Medicaid covers his tube feedings, feeding bags, syringes, and alcohol swabs, adding up to $700 per month. Hospitalization would cost $1,500 per day, or $46,500 per month, whereas home care costs about $17,000 a month.

I am so pleased to have Steven at home with us. However, juggling all of these resources is exhausting and difficult. Even with Group Health, the MDA, and Medicaid, my family was left alone to deal with the stress on my husband and me and the other children. Things like transportation, respite care, and social work should be included in policies that cover home care for children. Without comprehensive care, technology-dependent children do not experience the quality of life to which they are entitled.

Steven wanted to live. I wanted Steven to live. He adds immeasurably to our household. Living in a hospital just would not have been feasible. His quality of life at home, with family and friends around, cannot even be compared to a life in a hospital. No child should be denied the right to receive total care at home. I urge you to make provisions to ensure that all children who need home care can receive it. Thank you.

Chairman MILLER. Now we'll go to Daniel's mother.

STATEMENT OF DEBORAH RUSSELL

Ms. RUSSELL. I'm Deborah Russell, I'm Daniel's mother and I am here today with my husband Scott and our daughter, Margaret.

Daniel and Margaret are 4-year-old twins. They were born seven weeks premature. After four weeks in the neonatal intensive care unit, Margaret came home. Daniel's problems were more severe.

After 5 weeks on a respirator, he was given a tracheostomy. His condition continued to decline and he was transferred 150 miles away to Detroit Children's Hospital. There it was discovered that he had a rare congenital problem with his airway, which was causing it to collapse and actually grow shut. A specially made tracheostomy tube was inserted to hold this area open. The respirator tube had obliterated his delicate upper airway and paralyzed his vocal chords. For 5 months we were with Daniel as he was shuttled between the two hospitals. His condition went up and down. We had our tiny six-pound baby with us, our other baby, also.

Today, Daniel remains a child with a risk-obligatory tracheostomy. He's had about 30 surgeries to correct his problem and has spent several additional months in the hospital. From the beginning, we have been committed to having Daniel at home. We learned all of his care—suctioning, respiratory assessment, trach care, resuscitation, tube feedings, cardiac monitor use, respiratory treatments, OT and PT exercises, signing and speech therapy. Although we can do each element of his care, we are not able to provide it around the clock without help. We have managed Daniel at home most of the time between surgeries due to his successful home care program, which includes private duty nursing, extensive equipment and supplies and speech therapy. This has been a very complex and fragile arrangement involving dozens of providers, two insurance companies, Crippled Children money and medicaid waiver programs. In reviewing all the stresses of the past 4 years, the worry over financial coverage for the home care has been the biggest.

When our kids were born, I was buying the family's health insurance through my employer group. This covered 100 percent of Daniel's hospital care, but only 75 percent of his private duty nursing and 90 percent of his equipment and supplies. Of a $45,000-per-month hospital bill, we paid nothing. The same care at home required us to pay $1,600 a month of a $7,000 monthly bill. Even with good insurance, in quotes, the cost of home care was beyond our means.

We have not really been financially ruined as a result of Daniel's medical needs, but we have continually been faced with the threat of ruin and a steady reduction of our assets. Making the choice to care for Daniel at home has increased that threat. We requested the insurance company to waive the co-pay requirement since it would save money for Daniel to be at home, but it would not do so. After several weeks, Crippled Children's arranged to provide for co-pay on just the first 10 weeks of nursing. Then we applied for the new medicaid waiver in our State. At first we were denied because it wouldn't save the medicaid program any money. Someone sug-

gested that we admit Daniel to a nursing home and then perhaps he'd be eligible since our insurance didn't pay for that and medicaid would. Later his hospital bills did make him eligible, but then we were told he was ineligible because we had him at home. We were told we'd have to rehospitalize him for 30 to 45 days. We would not do it and we started contacting our legislators and doing everything else we could think of to pull out the stops. By then, we started getting rejections from the insurance company for their portion of the nursing bills. When we tried to follow up we were told Master Medical doesn't talk to customers. In the end, we were accepted for the waiver, but we still had to go through lengthy monthly recertifications and frankly, put up with continuous attempts to reduce the number of hours and the types of care, always by people who have never even seen our son.

When my husband was job hunting, a primary concern was insurance coverage for Dan. We were afraid to leave Michigan because we heard it offered the best in medicaid and Crippled Children's and special education programs. Scott's new employer has a reputation for taking care of its people and looked to have good insurance benefits. However, there was a 1-year wait on preexisting conditions. We hoped to keep my job until Scott's insurance would begin paying so we wouldn't be totally dependent on public sources. However, the waiver was cut back on our nursing and I was forced to quit.

Several months before Dan was to be covered by the second insurance, we started to work with their agents to determine what care would be covered. We were initially told that Daniel could be admitted to a nursing home which is 50 miles from our home because his care was, quote, custodial, unquote, and I still don't know what that means, and as such, it was likely that none of his care would be paid for at home. This was devastating and we also knew it was not appropriate. I think you just have to see Dan to know that. Finally 9 months later, the company agreed to pay for the care that Dan's physician ordered and I'm not particularly singling this company out. I think that this is just a problem with understanding what our needs are. I think this is one of the good companies, in other words.

Last fall, Daniel had a second attempt to rebuild his trachea using cartilage grafts from his ribs. He had complications which took him to the operating room an extra four times. He was placed on a ventilator, had IV feedings and medications to paralyze and sedate him. After this, Daniel was very weak and required respiratory treatments five times per day. He also was discovered to have a new problem called gastroesophageal reflex. Stomach acid was coming up and going down his airway, damaging it more. Daniel's care became so complex during the next months that he had procedures nearly nonstop and more frequent surgery, and I can tell you that our daughter was extremely neglected during that period and started having a lot of behavior problems as a result.

Dan's doctor asked for an immediate increase in nursing hours, but it was several weeks and we had still not heard from the insurance company. Finally I became so exhausted and anxious and depressed that I couldn't care for Daniel at all. We were forced to admit him to the hospital for 10 days and send Margaret to family

while I received medication and treatment for my stress. To us, admitting Daniel to the hospital under this situation was a terrible, terrible failure.

Our new insurance has an upper limit. In the first year, a quarter of it has been used. Once we reach the maximum, we'll have several options. We can change employers to find another group insurance, likely with the same limitations as the last, or take on the burden of his expense, which we cannot afford, or institutionalize Daniel, in which case all of his care would be covered by the government. We feel we're in a Catch-22 situation. Daniel's needs have left us also with additional costs and I'm not going to go into them because I think they've been covered by other people. I want to add that our families have been extremely supportive and helpful, although they don't live in our State.

Both our careers are limited now. We've gone from a two-career to a one-and-a-half to one wage earner family. The primary concern in making job and life decisions is insurance coverage to meet Daniel's needs. If the coverage is good and the claims are actually paid, we don't dare risk changing jobs. When the benefit limit is reached, you must move on. This is how we avoid financial ruin and keep Daniel at home.

When Daniel came home, he weighed only 8 pounds and he was 7 months old. He couldn't sit up. He looked like a little stroke patient. He was labeled, "failure to thrive" at the hospital. He couldn't lift his head, he was very weak. He was 3 months behind in his development, but he quickly progressed at home and he is now a normal 4 year old except for his speech problems, but his language comprehension actually tests a year ahead of his age level and he has a lot to say. Our kids have been able to grow up as siblings together. We are convinced that home care has made the difference in Daniel's healthy development.

As you consider remedies to the problem of catastrophic illness, I urge you to include all age groups in your solutions. Such solutions must address the overwhelming burden of chronic and long-term care and make the option of home care available to families.

In closing, I ask that you do whatever you can to make it easier for families to have their children at home with nursing care. This option must be available to families of all incomes because it will save money and because the kids will do better and because it's right.

Please don't penalize those of us who have insurance which doesn't cover home care by leaving us without help. Don't allow our public programs to lure families into taking their children home and then leave their families to disintegrate with inadequate long-term support. You will be destroying an important resource. It is our wish to be parents and provide a stable, loving family which gives our kids the motivation to achieve their full potential.

Thank you.

Chairman PEPPER. Thank you very much, Mrs. Russell. I'll let the record show that Daniel is a delight—a handsome, bright-eyed little lad of 4 sitting in his mother's lap. In his own lap he has his rabbit and he told Mr. Miller and Ms. Oakar and me the name of his rabbit and shook hands with us a little while ago when we passed by.

It just shows what the technology we have today can do if we make it available to those who otherwise couldn't get it.

Next is the Reverend Robert K. Massie, Jr., age 30 of Boston, Massachusetts, hemophiliac and former chaplain of Yale New Haven Hospital, an activist on behalf of chronically ill children. Reverend Massie.

STATEMENT OF REV. ROBERT K. MASSIE, JR.

Reverend MASSIE. Thank you Senator and Chairman Miller.

I have an additional written statement which I'd like to include at a later time if that's all right with you.

My name is Robert Massie. I'm an Episcopal clergyman from Boston. I wish that you could come with me today to my parents' house in Irvington, New York, which is where I grew up, and come up the stairs to our attic. I'd take you to the corner of that attic and show you a testimony of my past and that would be eight sets of leg braces, starting from very small size ranging up to the size that I wore as a teenager. I couldn't walk without these leg braces because I have chronic, severe hemophilia.

For those of you who don't know, hemophilia is a genetic disorder in which a person is absolutely normal except for the absence of one tiny protein caused in some cases by a single tiny genetic error. Because of this error, the blood does not properly clot. Now, many people think that the issue in hemophilia is external bleeding, but that is not the case. External bleeding can usually be controlled. The problem is internal bleeding, particularly bleeding into joints that have been stressed—and as a child running around, obviously there's a lot of stress on their joints.

I bled many, many times into my joints as a child and I missed literally hundreds of days of school. I could not walk because of hemorrhage into my left and then my right knee that took place when I was 5 years old. And when I was 12 years old in 1968, scientists discovered how to take this clotting factor and concentrate it into a high-powered special blood product which I brought for you today. It's a powdered product and for me, this concentrate, when it came out, was like a miracle. Instead of going to the hospital to receive care, wasting precious hours waiting in the emergency room until someone confirmed my diagnosis of hemophilia and then got some concentrate or fraction out of the blook bank, I could be treated at home. My parents learned to give me infusions and eventually, I, at the age of 14, learned to self-infuse.

This enabled me to have an independence that I could never have known before, to travel far away from hospitals, to cut that umbilical cord. It meant that I could travel by myself. It meant that I could go to Princeton University and graduate, that I could go to Yale Divinity School, that I could be ordained as an Episcopal clergyman and serve in my chosen vocation. It also meant that I could take all of those leg braces and carry them upstairs and stick them in the attic and leave them there forever. Now, the miracle that enabled me to walk again really came in two parts. This is one part.

But the other part was finding the way to pay for this. The cost of this single bottle of clotting factor is over $100 and I have to

have this at least four or five times a week. Over my life, I've had well over 5,000 such injections. This works out to an average of about $25,000 a year. Now, you can imagine the story that my family went through is extremely similar to all the stories we've heard this morning. There were very few, if any, insurance companies that were willing to touch us because I had a pre-existing condition.

Time after time my father sought insurance for me and was told that the company would be delighted to provide insurance for every member of the family except me. At one point my father was earning only $9,000 a year supporting a family of four and $5,000 of that had to go for my medical care. Fortunately, in 1968 my family moved to France and we found, when we were in that country, that blood products are freely available to all persons through their system of national health insurance. The miracle to me was that I was covered, even though I was not a French citizen, but only a foreign resident. That I can walk into this room today is therefore due both to American medical technology and to French political compassion.

Now, in the late 1970s the American Federal Government did decide to assist persons with hemophilia by funding comprehensive treatment centers which enabled some hemophiliacs to receive high quality care and also, to get it at home from their very earliest years. Several economic studies have been done and have shown that as a result of this federal commitment of only $3 million a year, there have been net savings over 10 years of well over $1 billion. Thousands of children who would have been doomed to live completely dependent and pain-filled lives have grown into energetic, independent and taxpaying citizens.

However, you know that there are still hundreds of thousands of Americans who have serious chronic illnesses—who are barred from insurance coverage—and I urge you to remember that we, who are here today, are but a tiny, tiny percentage of this hidden group. To me it is an outrage that in our great Nation we have a system that gives persons with the lowest medical risk and need the best insurance at the lowest cost whereas the persons who most need insurance coverage are given the worst insurance at the highest cost, if they can get it.

With regard to hemophilia particularly, there are still many serious problems to be faced. You may know that hemophiliacs are in constant danger of exposure to the AIDS virus, and private pharmaceutical firms are working now to develop a product which will be completely virus-free. The companies, however, plan to charge from 3 to 700 percent more than the current product. In other words, the cost for a person like me could go from $25,000 a year to as much as $175,000 a year.

Members of the Committee, there are thousands of Americans like me, but I must say that I was always extremely privileged. I had extremely energetic and dedicated and thoughtful parents, like many of the parents who are here today, and my parents had a profession which enabled them to apply special pressure—that is that they were journalists and writers. They were able to take their concerns and speak out and put it in print. They were extremely dedicated and committed so that when I was barred from

my local school, they insisted until I was finally introduced into the school system over the objections of the teachers who didn't know anything about hemophilia.

My parents were always resourceful. When they discovered that New York would not teach me to give myself infusions, they went down to Philadelphia. But there are many, many people who are not able to withstand the psychological and financial burdens of catastrophic illness with the same abilities that they showed.

There are many people who are simply crushed by the grossly inequitable system of health care we have in this country. The provision of medical care—good medical care—is critical. And home care for our children is as we've heard today not only medically sound, it's also economically wise—and to me it is morally imperative. So I urge you to take the steps that will allow these children, all children, to cast off the enshackling braces of their disease. I hope those of you in Congress will enable them to do as I have done, which is to walk freely at last.

Thank you very much.

Chairman PEPPER. Thank you, Reverend Massie, for your excellent presentation.

Mr. Miller, do you have any questions?

Chairman MILLER. Thank you, Mr. Chairman, I want to thank every member of the panel for their testimony.

I find it somewhat difficult to listen to it, I guess, and realize that I'm almost exhausted here after listening to your tales of trying to secure the resources necessary for the survival of your particular children, but also for your family. I think that I would be correct in saying that in many instances, you're the exception; that there are an awful lot of families out there who desire the same goal of some sort of home health care, some ability to have their children home, who simply have not even been able to obtain the level of home health care that you have. So as tragic and as exhausting as your stories are, in fact you are still the exception to the rule in the care of your children.

One of the things that also comes through the stories is the extent to which the illnesses of these children spill over, if you will, to other members of the family. If you read through the various pieces of testimony there's constant reference to trying to hold the family together and to deal with the natural stresses and the strains of marital relationships, of children's relationships with one another and with their parents through this entire ordeal. Then when you see something, as in the case of Joe, you're talking about here's your sister, 15 years old, who wants to go out and get a job, but Social Security is going to tell her she can't do that, or your family's going to have to tell her she can't do that, because those earnings would decrease her family's income and as a result, would diminish your ability to have support from the Social Security Administration. It is unbelievable, I think, to members of Congress, when in a sense we keep telling our constituents and ourselves that these are the families that we want to help. These are families who are showing self-sufficiency, tenacity, they're going out and banging on every door, cutting every piece of red tape and then we come along and continue to pull little pieces of the support system away from the families.

I don't know, maybe we should establish a bounty that you can have half of all the money you save either the insurer or the Federal Government, then you would be both wealthy and have care at home if the figures are as your testimony represents. You would all do very well because you've been creative enough and resourceful enough to turn either federal or private bureaucracies around for the benefit of those bureaucracies and for the benefit of your children.

Randy, in your case, you're telling us that the only distinction between the care you get at home and the care you get in the hospital and whether or not it will be paid for is the fact that you're not homebound by definition. Your care enables you to go out and to live an active life and as a result of that, you don't meet the definition of being homebound for purposes of reimbursement?

Ms. KRAMER. I can lead an active life. It's still limited.

Chairman MILLER. No, I understand that.

Ms. KRAMER. It's just the 6 hours it takes to get therapy when it's only 2 hours at home. There's a big difference. That's 4 hours I spend in getting therapy every day.

Chairman MILLER. But at that point for the remainder of the day you could then go on about your ordinary course of business.

Ms. KRAMER. Right and then I could exercise and do whatever I have to do and do my chores.

Chairman MILLER. But the fact that you have that remaining period of time now, does not qualify you in the sense of homebound, is that correct?

Ms. KRAMER. Right.

Chairman MILLER. To what extent do any of your families receive respite care from the State or other sources? Do any of the parents here receive any kind of respite care?

Ms. RECKEWEG. We receive skilled nursing care through the State of Maryland.

Chairman MILLER. But does that allow you respite care—I'm talking about just for your mental, physical well being.

I know in California we have a small respite——

Ms. RECKEWEG. They had 2 weeks in Arizona, if you're approved for the program.

Chairman MILLER. You mean you could get 2 weeks of respite care if you live in Arizona. You don't mean they're giving you 2 weeks in Arizona.

Ms. RECKEWEG. If you live there.

Chairman MILLER. OK. We had a poignant hearing about children with disabilities and in California we have a respite care program. I think they are giving 4 days a month and one young woman who was testifying had used 2 days of her respite care to come to the Committee to tell us about the lack of respite care.

Joe, when you're talking about nursing care you're talking about attendant care for yourself so you can go to school?

Mr. J. MILLER. Yeah, to put me into bed at night. You see, the way I am, it's hard to have a certain set schedule for nursing service.

They say I could have a nurse for 8 hours a day. Well, what 8 hours a day should I have the nurse there? Because at night to put me into bed, that takes about 1 hour to 2 hours to take care of my

needs at night and then once I'm in bed and asleep I generally don't need anything until the next morning when I have to get up and get ready for school. Then it takes about another hour, hour and a half to get me up in the morning.

And then from there, I never know what's going to be needed you know. One morning I can have an accident, where I have to have my pants changed, taken off and cleaned and put on another pair, or I may not be feeling good and I may have to stay home and have certain things taken care of and done—it's hard to say.

You know, you have to choose 8 hours day—well, what 8 hours do I choose?

Chairman MILLER. Do you have attendant care now?

Mr. J. MILLER. No, I do not. My mother is taking care of me and that's why she is unable to work. It's really hard on her because, you know, she's 5'4" and I'm pretty close to 5'10", and 140, 145 pounds.

Chairman MILLER. Have you had attendant care in the past?

Mr. J. MILLER. We had it for about 3 or 4 months after I had gotten out of the hospital and then it was refused by the insurance company, because they wouldn't cover it, I guess. They tell you in the hospital that they will try to get you coverage as long as they possibly can for when you leave the hospital where you have a full 24-hour nursing staff. But from there, they want to see how much time they can cut back on the insurance company because like they say, the insurance company only pays so much money up to a certain amount like——

Chairman MILLER. You're not entitled to attendant care under Social Security?

Mr. J. MILLER. That's what that $3.72 an hour is for and you can't hire a professional for that amount of money. That's like a little bit above minimum wage, you know.

Chairman MILLER. No, I understand. I understand very, very well.

We've been battling this out for some time and I guess, you know, young people like yourself—are you in school now?

Mr. J. MILLER. Yeah, I'm still trying to graduate. I lost a semester of school and so I'm struggling to gain credits.

Chairman MILLER. I know when I went to law school my neighbor and a number of my classmates were paraplegics and we were constantly being called upon in the morning because their attendants didn't show up or had taken that month's care and not shown up or what have you. We find time and again, that we keep trying to hire attendants on the cheap and that's exactly what we get—cheap attendants. It's very difficult even for people who want to be professional attendants and have trained themselves to make a living doing it. What we find is that people like yourself end up going through attendant after attendant after attendant after attendant with no stability or reliability in that system, so in this case, it's your mother who now once again is called upon to take care of you.

Mr. J. MILLER. I also rely a lot on a lot of my friends. They take me to and from school and help me with other needs I may have, you know, we sit there and we hang around together, we go out on weekends. Without a lot of my friends, I'd be stuck in the house

about, I'd say, 95 percent of my time. Right now I'd be stuck at home if it weren't for my friends.

Chairman MILLER. Let me ask one other question and that is, the other thing that seems to be common throughout this testimony is the marked improvement in the children when they do come home, in the attention they get. So often when children are institutionalized in hospitals for great lengths of time, it's simply the inability of the institution to try to even hope to deliver the kind of care that you as parents might. That just seems to run throughout this testimony. In Jeff's case, you talk about him being docile when he first came home and the same was true of Daniel to some extent. Obviously neither one of them are at this point, they're well behaved, they're just not docile.

God forbid a Congressman would criticize somebody's children. If you need me to kiss them, I will later.

But I think that's important you know, because two things happen to us in the Congress. One is that, as I sit on the Budget Committee and we are considering all these medicare and medicaid changes right now, we're only given the credit for the increased expenditures. If we were to provide the language change in CHAMPUS or in Medicaid or Medicare to allow reimbursement for home health care services, we would all get chalked up with additional spending. There would be no credit for the savings.

The other thing that happens is there is no way to figure into that equation what it means to the child and to the parent, to the relationship and to the healthy development of that child. There obviously is no bookkeeping mechanism to handle that, but it is clearly something that this Congress is going to have to come to grips with.

I just want to thank you very, very much for your testimony and thank the children very much for being with us this morning. I think the case has fully been made. Once again, this situation is what so very often we say we want to address and now it's here on our doorstep and it's affecting millions of American families and it has little or nothing to do, as we have found out, with age. And I think we're going to have to be much more expansive in our attack on this problem that really, really threatens the stability of these families no matter how good, how resourceful you are.

I don't know many families that can live under that kind of 24 hour, 365 day stress and you are really to be commended for however you've been able to cope with it.

Thank you, Mr. Chairman.

Senator PEPPER. Thank you, Mr. Miller. Ms. Oakar.

Ms. OAKAR. Thank you Mr. Chairman. I thank the panelists.

I guess the frustration that I am experiencing along with my distinguished friend, Mr. Miller, is the fact that I honestly believe some of the problems are with the regulations, not with the legislation.

Susan told us, and we were glad to have you share that with us, about her father and I believe he was in a hospice program.

I recall several years ago when the administration changed its hospice program regulations so that in effect, it wiped the hospice program out. The fact is, we legislated the right thing, but the regulation was problematic and in the case of Randy, it seems to me

that HHS is making a broad interpretation of what your needs are. Apparently, the way they interpreted that regulation is that you are supposed to be restricted to a bed for several hours and so on. There's nothing that I know of in the legislation that talks about the hours. I could be wrong about that, but then in this case, I believe, Mrs. Reckeweg or it might have been Mrs. Sutton, you were talking about what your State gives out as options for home care and you just don't happen to plug in, but I'm not so sure it's the legislation that has been passed by your legislature. It might be the interpretation of the bureaucrats and so I think right away what we might want to do just as we did for the hospice program we might want to look at the regulation, the regulations of some of these things.

Systematically, I've seen interpretations of regulations of the last few years being contrary to the spirit of the law so it seems to me that there might be some interpretation that we might want to get into in analysing some of these programs.

For example, and I gave one earlier, you have a situation where some bureaucrat—the inspector general, who thinks he's a doctor of HHS—has now said that even though the doctors feel that these kids should have access to their lifeline so they could call a friend or their classmate or something or their parents, he says that it's against the law and only Federal employees should use that and yet, prior to that, these 40 kids were able to call people as part of their ability to have some hope and that's a regulation. I just think that we ought to take a look at this regulation.

The other point is that the quirk of the medicare law that says that you have to be able to learn for a certain period of time when, you know, it's just backwards it seems to me and I think that those are doable kinds of corrections right away.

However, I must say that as much as I am very, very supportive of home health care, the real answer is you need a comprehensive policy. I mean, we ought to come to grips with that. You shouldn't have to go to France to get your medication paid for and this is what some of us have tried to do and it's an old idea, but I don't know why we don't have national health insurance in this country. It's just crazy to me, but let me ask you, Steven, your mother says that you decided—well, you said too that you decided and you said this on this great film which I hope is going to be syndicated. I hope somebody picks it up so people in the country can see this fantastic film that Susan participated in, but you said that you made the—your doctors, you know, a lot of them and there's some marvelous doctors. We have one in Congress, as a matter of fact.

But you said that your doctors kind of encouraged you not to undergo this surgery and you wanted to.

Mr. BROWN. Yeah.

Ms. OAKAR. How did you make that decision?

I mean, who gave you the impetus to challenge them?

Mr. BROWN. Well, my mother and my stepdad had a meeting and a conference and they felt it was worthwhile. My doctor at Children's Hospital, for humanity sake, didn't want to see me suffer, so they gave me the option to have the trach or not. It wasn't very encouraging, but I'm glad I had the trach.

Ms. OAKAR. And you're a good artist, right? Is that what you want to do professionally one of these days or what do you want to do?

I'm still deciding what I want to do when I grow up so what would you like to do when you grow up?

Mr. BROWN. I do pen and ink when I have strength to do it and right now I'd like to make a business of it. Whenever I draw something, I give it away.

Ms. OAKAR. You give it away?

Mr. BROWN. To friends, yeah.

Ms. OAKAR. Do you ever think you're going to get involved in that commercially?

Mr. BROWN. Well, I don't know. Unfortunately, I don't have a whole lot of strength, but I do what I can.

Ms. OAKAR. Mr. Miller, what do you see yourself doing in the future?

Mr. J. MILLER. Personally, I am going to try to get into psychology, become a psychiatrist—either that or radio broadcasting, one of the two. They're the same.

Ms. OAKAR. Same thing, right?

And we have Rev. Massie, who already is an example of somebody who's in a career.

Mr. Chairman, I just want to say I think what we're talking about, beyond everything else is the value of life. How much do we in this country value life and that's what I think the hearing is all about and I think we ought to pass a bill real fast and change those regulations as well and put the administration, not to make this partisan, on notice that at least things that we have something to say about, that they ought to not be trying to thwart the law that's already on the books.

Thank you.

Chairman PEPPER. Mr. Rowland.

Mr. ROWLAND. Thank you very much, Mr. Chairman.

I think that we have heard a common theme that ran through all of this testimony here this morning. I believe that Randy set the tone for that when she talked about the contradictions in the system. The fact that she was trying her very best, in spite of the terrible handicap, to live in society, make a contribution to society, and enjoy life and then was penalized by doing that.

I think that set the tone for everything and I listened to Angie talk about CHAMPUS and exactly the same contradictions take place there. Angie, there are some changes, I hope, that are coming in CHAMPUS now. You are probably aware of some prototype studies that are being done to try to change CHAMPUS making it an HMO type concept where those kind of contradictions will not exist and I certainly hope that works out.

Basically I agree with you. I don't think the administration ban will work. I don't think the plan that has been introduced by some members of the Ways and Means Committee will work.

It only covers about 3 percent of the medicare population—it only is for extended acute care in the hospital. It doesn't cover home care, nursing home care, prescription drugs, or physician's fees. It doesn't cover any of those things. In my opinion, it's just

another one of those bandaid type proposals that's being made and it just really doesn't address the problems that we have.

Sandy, you talked about you couldn't stay at home even though it would cost less to keep your child at home. It's just a shame that we're not able to deal with that in a manner. Sometimes, we are going far beyond what we need to do, looking for answers, when the answers are right in front of our face and I certainly agree with you.

And Joe, you said that your family had been put into the position of going on welfare. You know, that's a thing that we hear so often is that people, families deplete all of their assets and then they find themselves in a situation where they become dependent to a point that they really don't need to be. We must find some way to address that.

Steve, living at home means everything to you. So many people don't understand that. They just take for granted that they can live at home and how great that is, but you realize that that is so important and most people don't even understand that.

And Deborah, you find it cheaper to have your child in the hospital than taking him home. I think that we'll find with the catastrophic insurance proposals that that's exactly what's going to take place. Families will find it is going to be cheaper for them to try to keep the patients in the hospital. In these cases, we may find families and doctors and hospitals in an adversary situation if that insurance passes because the families, many times, want to keep the person in the hospital rather than take them home.

And Robert, I was listening to you about your hemophilia and when the concentrate came along, it was really a boom. I did family practice for several years before I got into Congress and the joint problems were just almost overwhelming. I had about three hemophiliac patients that I treated and when that came along, it just really made a tremendous difference.

But, Mr. Chairman, we've heard this common theme that ran throughout this testimony this morning and I think our Chairman, Chairman Miller, touched on this. I think that we are now finding that economic considerations are running head on with moral and ethical and humanitarian considerations and it is very difficult to deal with.

I don't know how we are going to solve this problem. Congress is moving constantly trying to shore up the holes that appear in the dyke, trying to stop it here and it breaks out somewhere else.

It seems to me that Congress must stop, stand back and take a look at what we're doing. I think it's time that we look at the system that we have in this country. I believe that we're headed towards a national health service. What you got in France certainly made you feel a lot better, but I think they'd be running some 35 to 40 years behind the British experience. We'll wind up with a system of socialized medicine national health care that will not be in the best interest of the people of this country.

I think that we are going to have to step back and look at what we are doing and stop the bandaid approaches that we've been taking over the past two decades that I have been watching this very closely.

Mr. ROWLAND. I really thank all of you very much for coming today. The testimony that you have given certainly focuses on the problems that we are having in the country.

Chairman Pepper, you mentioned the new technologies and how much they are doing to help people in this country, but it's presented as a whole new area of problems that we didn't have 25 years ago. This new technology has thrust us into an area now that we must find answers for the questions. Thank you very much.

Chairman PEPPER. Thank you, Mr. Rowland. Mr. Vento?

Mr. VENTO. Mr. Chairman, I have no statement at this time. I commend you for the hearing, and look forward to hearing from some of the additional witnesses this morning.

Chairman PEPPER. Mr. Miller, I know what you have in mind. You think if you start off as a radio broadcaster, you, too, may wind up as President of the United States.

You noticed in the testimony of Reverend Massie, that he told about his family living temporarily in France, and how they got the medical care that they needed. The only two industrial countries in the world that don't do that for their people—do you know who they are? The United States of America and South Africa. That's the company we keep. And we see the tragedy that follows in the wake of that callousness on our part.

Now, there are some very pertinent observations that derive from this wonderful panel that we have had here this morning.

The first is, in general, all of you have testified that the patient having available the technology that was available in the hospital at home, does better at home than in the hospital.

Isn't that the consensus of this group? And the second thing is that it costs less, with the technology available, to provide that technology in the home, than it does in the hospital. Isn't that the consensus of all of you here?

The third point is the cost that you have to incur, either in the hospital or in the home, to take full advantage of that technology, is prohibitive to the ordinary family. Isn't that the testimony of all of you here today?

Then, what is the alternative? You have to have some help, some sort of support system needs to be designed, or else you suffer. There are those of you living today here before this committee, who wouldn't be alive if you hadn't had the technologies and the assistance that you have had. I think all of you will agree to that.

Now, what do we need to do? All we need to do is to apply the principle of insurance. Some of you spoke of insurance policies that have been helpful. Generally speaking, I don't know of any insurance policy that gives comprehensive care to any individual covered by that insurance policy. The insurance companies have made a lot of progress. They're taking a more advanced attitude toward the subject. I hope they will continue to do so.

My bill, H.R. 65, does provide comprehensive coverage to the elderly, and I'm introducing another bill that will provide comprehensive coverage to everybody. We hope the government will use whatever we formulate—a program that will take care of the needs that you have presented here today, which will utilize HMOs, insurance companies, hospital associations, doctors' groups and private enterprise, as much as possible, to implement the program

that we announce, in order to provide the service. And we want the maximum coverage. I sat down the other day in Miami Beach around a table with a lot of elderly people, and I had been talking about some of the things that you have discussed here today.

A lady from Canada was at the table. She said,

> You know, I don't understand. All these things, if they had occurred to me in Canada, would be taken care of, under our programs. I don't understand why your country doesn't provide some way by which these catastrophic things can be taken care of.

Somehow or other, certain people have put into the public mind that if we develop a comprehensive program, like Social Security, based upon the people making a small contribution each month. Some people couldn't pay it and we would of course have to pay it for them, or pay part of it. Under my bill, everybody would pay something, even if it's only a dime. I'd like everybody to pay something. But we can develop it as we've done with Social Security.

We require people to deduct from their monthly paycheck or their biweekly paycheck, a certain contribution to the Social Security trust fund. And when you retire, you get a Social Security pension.

I've talked to thousands of people who receive Social Security checks. I have yet to hear one say, "I'm sorry that mean old government made me deduct from my paycheck a contribution to that trust fund." They're mighty glad they did. It gives them a nest egg they otherwise wouldn't have.

And we can develop, if Congress will overcome the fear that some demagogues or some people who are falsifiers of the facts, have installed in them by calling it socialized medicine, which is, of course, a first cousin of communism—we can develop a system of comprehensive health care in this country. I do not believe you are a Communist if you want the people to get the medical care they need.

The fact is, we are faced right here and now with a rare opportunity. I am sure my colleagues will agree that Congress is more favorable to do something meaningful in this field that we have been since I came here over 50 years ago.

We have a long way to go, however. Just the other day when I appeared before the Ways and Means Committee, the Chairman from California said, "you know, I approve of everything you said. I want our staffs to work together. We want to get the best bill we can."

We need to give special help to the people of the middle class. We thought in 1965 when we passed medicare that it would take care of the old folks and then we would take care of the very poor with medicaid. We thought the middle class could take care of itself. All of you people here are good, middle class Americans. You see the problems that you've had to face.

And so it's those middle class Americans that suffer—I'll just mention two cases. My subcommittee had a hearing recently. I had a letter from a man 83 years old from Maine. He said, "I'm one of the loneliest men in the world. My wife of 55 years developed Alzheimer's disease. I had to put her in a nursing home. And then, I had a stroke. One of my legs had to be amputated. I had some other disability. Now I'm struggling to take care of my wife in a

nursing home and we've almost used up our savings of $160,000." You've referred here, some of you, to several hundred thousand dollars in medical expenses. How many Americans have got $160,000 in the bank? I know I don't. And I think most Americans don't.

Another fellow said,

> I was 58 years old. I was in good health. I had a good job. My wife and I owned a comfortable home. I had four insurance policies. Then, I got the word one day that my wife has cancer. Then, shortly after that, I had a stroke. Shortly after that I had an automobile accident. The result is, I have been struggling to keep my wife in a nursing home, which is not covered by Medicare, and we have almost used up our $140,000 in the bank—our life savings.

We had four witnesses before our committee the other day. All of them were good, middle-class Americans just like you all are. In the long run, every single one of them had to sell their home.

I'll never forget the agony of one lady. She said,

> My husband had Alzheimer's disease and I was trying to keep him in a nursing home. We used up our savings and we had to sell our home. But I dared not tell him that we had to sell our home, because it would have broken his heart.

So if the citizens out there just realized the jeopardy they are in, they would tell our Senators and Representatives, listen, you sit down and work out a sensible, reasonable, sound American program, under which we can provide a means by which the American people can get the medical care they need.

Excuse my speech. But anyway, I just wanted to say those things. And thank you, every one of you. You have been wonderful witnesses this morning. Thank you very much.

Our next panel is on the dimensions of the problem, they will please come up as their names are called.

The Honorable Frank Moss; the Honorable Charles Percy; the Honorable Dr. James Perrin; the Honorable Dr. J.D. Northway; and the Honorable Dr. Josephine Gittler.

Will you all please come up here?

Our first witness is a very distinguished former colleague of mine in the Senate, a man who has been a leader in the field of health care for the American people for a long time, the former U. S. Senator from Utah, Chairman of the Board of Trustees of the Foundation for Hospice and Home Care in Washington, DC, my friend and a great American, the Honorable Frank Moss.

PANEL TWO—THE DIMENSIONS OF THE PROBLEM: CONSISTING OF HON. FRANK MOSS, FORMER U.S. SENATOR, AND CHAIRMAN, BOARD OF TRUSTEES, FOUNDATION FOR HOSPICE AND HOME CARE, WASHINGTON, DC; HON. CHARLES H. PERCY, FORMER U.S. SENATOR, AND VICE CHAIRMAN, BOARD OF TRUSTEES, FOUNDATION FOR HOSPICE AND HOME CARE, WASHINGTON, DC; JAMES PERRIN, M.D., DIRECTOR, AMBULATORY CARE PROGRAMS, CHILDREN'S SERVICE, MASSACHUSETTS GENERAL HOSPITAL, BOSTON, MA, ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS; J.D. NORTHWAY, M.D., PRESIDENT AND CHIEF EXECUTIVE OFFICER, VALLEY CHILDREN'S HOSPITAL, FRESNO, CA, ON BEHALF OF WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS; AND JOSEPHINE GITTLER, J.D., CODIRECTOR, NATIONAL MATERNAL AND CHILD HEALTH RESOURCE CENTER, UNIVERSITY OF IOWA, IOWA CITY, IA

STATEMENT OF HON. FRANK MOSS

Senator Moss. Thank you, Chairman Pepper and Chairman Miller.

I am pleased and honored to have the opportunity to appear before this joint hearing. And I want to commend you, as chairmen of the two great committees for bringing them together.

We are coming before you today to present a report of the Foundation for Hospice and Home Care. The report is entitled "The Crisis of Chronically Ill Children in America, a Triumph of Technology and a Failure of Public Policy."

[See Appendix 1 for report referred to above.]

Senator Moss. Now, Senator Percy and I, who were here this morning, sat and listened to the testimony of that great panel that you just had, and it seems to me they told the story so eloquently that it could not be missed in any way. And the summary made by Chairman Miller and then by Chairman Pepper indicated the strength of the message they gave. All the other members of the committees indicated they had the message. We are happy that we can present this report to you, because there is entirely too much in the public press of late on what some people call the battle over scarce resources. What some critics would have you believe is that the Nation's children and the Nation's elderly have little in common. They would have you believe, depending on their point of view, that either the Nation's elderly or the Nation's children, are receiving a disproportionate share of our resources. They would also have you believe that we can't afford to provide the basics of decent health care for all Americans. And therefore, these critics assert that we should choose one group or another for our efforts and our resources.

I was so pleased to hear how eloquently that was answered from members of the committees. This hearing proves that all of this doom-saying is nonsense. The Nation's older, infirm Americans and its disadvantaged youth have much more that unites them than they do that separates them. For one thing, the two groups are united by their need for care and by their relative vulnerability. No one is going to persuade me that we do not have enough re-

sources in this great Nation to provide the rudiments of adequate health care for our elderly and for our children.

I am convinced that working together with your committees, we can serve as a catalyst to help bring the Americans together.

If I may, I'd like to say a few words about the Foundation for Hospice and Home Care, and then I want to follow with some general conclusions of our report. Senator Percy will then highlight our findings in a little more detail.

Our foundation began with the premise that senior citizens are a neglected and underutilized resource and none more so than retired Members of the U.S. Senate and the U.S. House of Representatives.

It was my idea to bring these former members together as trustees of a foundation and give them an opportunity to contribute once again. As you can see, our foundation board includes an impressive list of former Members of Congress. To this nucleus, we've added other interested celebrities and an occasional sitting Member who has expressed a special interest in supporting our activities.

The scope of the foundation's interest is framed by a quote of our old friend and former Vice President, Senator Hubert H. Humphrey, who talked of the crucial need to help those Americans he described as being on the fringes of life. These are our chronically ill children who suffer health problems in the dawn of life, our elderly citizens with compound burdens in the twilight of life, and our disabled, who he said have been relegated to the shadows of life. Those are the Americans with whom we are concerned.

Our foundation conducts research on timely topics. We do this through what we call the Caring Institute. We hold hearings just as this Congressional hearing. And we have assistance of staff and have interviewed citizens and experts. The data which we gather are fashioned into reports which we release to the public and to appropriate committees of Congress for consideration. We plan to augment these activities with the production of visual documentaries such as the one you saw this morning. Chairman Pepper and I hope all will have a chance to see it. It's a wonderful, marvelous film, and tells the story so eloquently. Many of the stars of that film sat at your table here this morning.

Permit me now to tell you a few words about our report. It is based on 2 years of research. It examines what I call a blight on the American conscience—the clear deprivation of the civil rights of some of our most vulnerable members of society, who are our chronically ill children.

We investigated the troublesome fact of thousands of American children being kept in institutions, for no sound reason. They want to go home. It is better for them to be at home. The families want them home. And certainly it is better for society and a better use of our resources to care for them at home. The sad fact is that most of these special children have been deprived of their freedom and are being robbed of an opportunity to grow and develop to the full extent of their God-given abilities for no reason.

Day after day, they are required to live a regimented, regulated existence, often confined to rooms without windows, isolated from their parents, their brothers and sisters, and from all of society. They spend months if not years under hot lights in tiny cribs,

never seeing the clouds, the trees, or the other wonders of nature. They have never had a chance to hear a bird sing, or smell bread baking, simple things that other children take for granted.

The crime these youngsters have committed is to be born with a less than perfect body in a society which prizes perfection. The length of their confinement can be for months or years, even for life.

As with other such similar confinements, rationalizations are offered which have little to do with the facts. It is asserted for example that placing them in this restrictive setting is for their own good, or that even if this setting is not for the child's best interest, society simply has no alternative. Others simply argue that confinement is in the best interest of society in general.

The plain and simple fact and the major conclusion of this report is that these youngsters could and should be home with their parents. The fact that they are not represents a collosal failure of public policy.

So the natural questions are: who are these children and how many of them are there? These children are largely a gift of modern science. Modern technology has allowed us to save the lives of thousands of infants who previoulsy would have died. Many of these children were born premature, and for that reason, sometimes, their internal organs did not fully develop. In other cases, the youngsters are carried full term but suffer from congenital disabilities. Others are injured by accident or neglect. And I think you saw examples of every one of these categories.

Many of these children fall into 11 categories which have been called marker diseases. They are leukemia, cystic fibrosis, congenital heart disease, spina bifida, asthma, hemophilia, chronic kidney disease, juvenile diabetes, muscular dystrophy, cleft palate and sickle cell anemia, and a small but rapdily growing number are children who are the victims of AIDS.

According to reliable estimate, there are 10 to 12 million children who suffer from some degree of chronic health impairment. Some 2 million of these suffer from severe chronic illness. To these numbers must be added several million children who are the victim of accidents, including burns.

This smaller group of children currently account for about 40 percent of all pediatric in-patient days in U.S. hospitals. Many of these youngsters live in pediatric intensive care units of the Nation's hospitals, and some live in total isolation.

Some of these children are called technology-dependent, a reference to the fact that they owe their very lives to modern technology, and continue to be dependent upon it to some extent. It is the evolution and refinement of such technology which makes it possible for these special children to be cared for at home.

You have already seen and met some of these youngsters. You have heard their families speak of their struggle. You have heard in particular their problems in obtaining the necessary funding to support the care of the children at home.

I want to stress for you one vitally important point. Unlike other problems that you face, this one is susceptible to fairly easy solution. Moreover, the solution should not be more, but less expensive

than the patchwork of current programs that are so inefficient and generally so unhelpful to the family.

The simple message that we bring today is that the United States' policy has not changed to keep pace with technology. We are spending millions of dollars now through government programs and families are spending millions more in private health insurance, to keep children in institutions. The sad fact is that not only are we depriving the children of their Constitutional right to humane treatment, in the least restrictive environment possible, but we are pulling the families apart, and are also spending four or five times as much money for their care in institutions as we would spend if the children were cared for at home.

The problem here is that the present government programs either provide little help or they contain an institutional bias. As noted, this means that parents of chronically ill children must face a Hobson's choice. They can either keep their baby in the hospital, knowing that care will be provided and the bills will be paid, or they can bring the child home knowing that little or no financial help will be forthcoming.

In closing, I would like to say that I believe there is an almost universal agreement that the Nation needs to enact a catastrophic health program in the reasonably near future.

Moreover, there is beginning to be a strong consensus that the major gap in our health care system is long-term care. I think our report demonstrates beyond question that long-term care is neither synonymous with nursing homes nor limited to the elderly.

Long term care relates to functional impairment and disability and to the need for assistance in performing the activities of daily living. These Americans with chronic illness will need help not on an intermittent, episodic basis, but over long term.

I would ask you to consider the needs of the chronically ill children in any long-term care proposal which you might wish to incorporate into catastrophic health proposal. A national policy must be fashioned which allows for the long-term care of both children and older Americans. This policy must be based on providing care at home whenever possible and preserving the sanctity of the American family.

The problem of chronically ill children is going to increase in the years to come. It is vital therefore that the Nation come to grips with the problem. We must develop a policy which restores to these infants their full complement of Constitutional rights. Our failure to do so will not only deprive the children, but impoverish our society as well.

I think that the message has been so clearly given and I do compliment these two committees for sitting together to hear the incomparable testimony of the people that are involved with their children and families with this.

I now ask that Senator Percy go ahead to present a number of the detailed conclusions of our report.

Chairman MILLER. Senator Percy, welcome to the committee.

STATEMENT OF HON. CHARLES H. PERCY

Senator PERCY. Thank you, Chairman Miller and Chairman Pepper.

Before Senator Pepper leaves, I just want to thank you, Congressman Pepper, for being an honored trustee of the Foundation for Hospice and Home Care.

I would like to say, Mr. Chairman, this is the first time as a private citizen in over 25 years that I've had the privilege of testifying before the House. I did before the House Ways and Means Committee 25 years ago and in my 18 years in the Senate, I did a few times, of course. But this is an occasion, when two great committees come together, committees that engage in some of the most worthwhile and meaningful work that the Nation carries on.

And when you combine the problems of the elderly and the problems of children and youth, this becomes a historic hearing and one that I will not soon forget.

I think that we should recognize that certainly as De Toqueville discovered in 1832, that voluntarism in the United States is one of the geniuses of this society. This point is certainly demonstrated by Foundation for Hospice and Home Care. Essentially the work that is done by hospice and home care with the terminally ill is equally voluntary—75 percent of that work is done by volunteers. Doctors, nurses, social workers, clergy and private corporations, business people all help. Over 50 corporations last night participated in putting together a benefit for Hospice and Home Care's foundation.

I'd like to insert in the record with your permission, Mr. Chairman, a list of the volunteer companies that participated with us.

We had some of the families that appeared before you attend that dinner, to see the efforts being made on their behalf in the voluntary capacity, in raising private funds to carry on the work of Foundation for Hospice and Home Care. They made possible the production of the film, "Suffer Not the Little Children", which was narrated by Susan Sullivan, a distinguished person who was with us all last evening, shared the evening with many others, and helped inspire them, as did Senator Moss and others that came with us. Senator Pell, the Chairman of the Foreign Relations Committee, and Senator Brock Adams, came to be with us simply to work on the problems that your committees are facing today.

It's my great pleasure to just boil down for you as quickly as I can some of the conclusions that we have received that we have reached in this extended report, "The Crisis of Chronically Ill Children in America, Triumph of Technology, Failure of Public Policy," and to point out what we need to do in the area of public policy. We want to be as specific as possible as to what can be done now to put into effect and implement the testimony that has been given and will be given following us today.

We heard Senator Moss speak eloquently of the need to provide assistance to meet the long-term care needs of all chronically ill Americans, young and old alike. Senator Moss is in a good position to speak on this subject, having served 18 years as Chairman of the U.S. Senate Subcommittee on Long Term Care.

For most of that time, I had the privilege of being the Ranking Republican on the Subcommittee. I was also fortunate enough to

serve as the Ranking Republican on the Senate Select Committee on Nutrition and Human Needs, chaired by Senator McGovern, and to serve on the Select Senate Committee on the Aging. I had to give up the Joint Economic Committee to serve on that committee. But I just really decided that shift should be made. I was an economist, but there are a lot of economists, but not as many people that were really looking at that time after the elderly. Certainly, we had Claude Pepper right here in the House. I just was thrilled to do that, and I'm thrilled in my third career now to carry on that work.

From this perspective, I'd like to say that the problem that you are addressing today is among the most significant which this Nation will face in the balance of the 20th Century. There is need for reform and change and for the establishment of a coherent public policy.

Among the major findings of the foundation's report are first, contrary to some mythology, most families do not abandon their children when born with birth defects. Most parents accept them and want those children home.

Second, physicians are in general agreement that it is possible to manage the care of most chronically ill children at home, even complex cases involving multiple disabilities.

You've heard testimony this morning from wonderful parents that have enriched their own lives and the lives of everyone that knows about what they're doing, as a result of being able to care for their children at home.

Third, physicians are in general agreement. Criteria for discharge from the hospital into the home are the child must be stable; the transfer home must improve the child's quality of life; the parents must be willing and able to take on most of the child's care; and adequate community and financial support must be available.

The fourth conclusion we came to in this report was that the major factor which stands in the way of bringing most children home is lack of funding. Either no funding exists or ironically, there is a bias in government programs in favor of institutional placement even though home care is more cost effective.

So here we have a chance to go for something that really would help us achieve Gramm-Rudman-Hollings. It will cut the cost and it humanizes the problem far more.

Fifth, therefore, most government programs, we conclude, such as medicare, medicaid, CHAMPUS and Crippled Children's Services, provide little in the way of home care services for children, even though it's the most economical and the most humane way of providing care. Somehow we've got to change and shake up the bureaucracy.

And then Sixth, most major private health insurance plans contain the same bias toward institutionalization, with no, or at best, highly limited, coverage for pediatric home care services.

I couldn't help but think, as I saw the Wall Street Journal this morning. Here's a picture of my son in law, Jay Rockefeller. And he is espousing the fact that whenever we see new technologies abroad, we shouldn't hesitate to adopt those technologies here. So,

too, I felt when we have technologies here we can share abroad, we ought to help encourage them to accept our aid.

I couldn't help but think of the time that I had as a Senator when I tried to help a constituent get their product into Japan and we found the bureaucracy in Japan simply impossible to break through. For 6 years we couldn't get the idea through.

The idea was very simple. An idea that's used here. Kidney dialysis. Patients must go into the hospital three times a week, 15 hours a week, and hook up to those machines and just stay there. How does a person working, how does a student at school do that, and not totally disrupt their lives?

And then a development came along, CAPD, by Baxter Laboratories. It's a system whereby a patient can be trained to carry a little bag and sack around, the blood will be cleansed while they're working, while they're at school, so forth. And yet, the bureaucracy in Japan couldn't be broken down.

After I left the Senate, I went over there, and Senator Mansfield and I went over and I just wanted to finish up some of the work I had started. We saw Prime Minister Nakisone and explained it to him. And when we got to the top, the bureaucracy saw the reason, it would free up thousands of lives, young and old, it would make for more efficiency, it would reduce the cost of the programs and the flexibility to that person is just unbelievable. In 3 months, we broke the bureaucracy down and they changed. And the 6 year battle was over. My son in law was saying, well, if they can do it, we can do it. We can break our bureaucracy down. We can change all this format that I have mentioned that makes it restrictive and difficult for home care and see if we can't ease the path to have these children, older people and so forth, cared for at home.

So seventh, a few insurance companies, such as Aetna Life and Casualty, provide reasonable coverage which pays not only for hospitalization but also facilities the provision of similar services at home. So the private sector is trying it out. It's working. Let's see that it moves forward. Aetna's program had the additional advantage that it saved their company $36 million in 1985. And that means insurance premiums went down by that amount. So it can be done.

My eighth point of the report is simply that thousands of children live in hospitals and institutions not because they need to be there, but because it's the only place where reimbursement is available for their care. Prolonged hospital stays pose significant problems, including delayed development, inhibited bonding between children and their parents, increased stress for the families, reduction of the stimuli and freedom necessary to produce the highest quality of life, and even increased risk of infection.

Ninth, home care has significant advantages for most chronically ill children. Among them, according to the experts are, high quality of care when the parent is properly trained and assisted by health care professionals, a more positive environment, which often leads to improved physical and mental development, reduction of family stress levels, cost effectiveness, more freedom for the children, promotion of the family unit, and a higher quality of life.

Certainly, delivering Meals on Wheels programs help. I went out for a week and just delivered them to homes of the elderly, the

young who were confined to their homes, and found out what a marvelous program we had in being. That ought to be strengthened in every way it can. And that enables people at home to stay at home and not have to go to an institution where the cost is astronomical.

The tenth point of the report is that service coordination or case management is a very important part of a successful pediatric home care program. What this means is that someone must accept responsibility for coordinating all the care and services that the child needs. Parents need the assistance of a social worker or other health professional to help them get the supplies and services that are necessary to maintain the child in the home. This help is needed in part because the current system is so fragmented and disorganized that it takes skilled hands and experience to navigate through the maze and reach the goal of quality home care.

The eleventh point to be made in the report can be summarized in simply this one sentence. Even after parents had been successful in bringing their children home, they lived with dangerously high levels of stress.

Twelfth, families and medical professionals alike are in strong agreement on the need for respite care to ensure the success of any pediatric home care program. Families need a break from the pressure. Parents need some time to themselves, an opportunity to run errands, to take care of their own needs or just to rest. A short respite will allow most families the chance to gather the strength they need to continue to provide safe care for their children.

Thirteenth, one of the primary conclusions of this report relates to the need to educate the American public. This committee and these hearings will do a tremendous amount to accomplish that. Relatively few people understand the extent of the technological revolution. Only about 40 percent of the American public knows about home care as an alternative to keeping chronically ill or severely disabled children in the hospital. There is a need to inform affected families in particular, since most of them have nowhere to turn when their child is born with long term health care problems.

The proceeds from our benefit dinner last night for the Foundation for Hospice and Home Care, to a large extent, can go out to educating the American people so they will come in to their own hospice centers in their own communities and say how can you help us, how can you work us out of this particular problem we have?

Fourteenth point and the last one of the report, and one that is very meaningful to me, and we saw it here today. Families are in agreement that despite all the pressures, having and caring for one of these special and fragile children is the highlight of their lives.

I think many of you know my daughter Sharon, her twin sister Valerie and our son, Roger—three little children, at the age of 1 year for our son and 3 years for the twins—my wife died. And I had those children for 3 years alone. Trying to run a corporation at the same time, and whenever I'd have to go to Detroit for a board meeting, I'd put them on the train with me, have a nurse meet me. Those children, for 3 years, I saw the wonderful thrill a parent can have in taking care of the needs of those children. I experienced

that same thrill as I talked to these parents last night and talked to some of them this morning.

What a wonderful thing it is, what it does for everyone that knows them. I've seen it so many, many times, that I just urge we move our society to the point where we can manage to see that home care is a part and parcel of the health system of this country.

I have nine points; I'd like to just yield to the other witnesses we have here and ask your permission to incorporate these in the record. They take about 2 minutes more and they're the final recommendations we have for your consideration.

If you're tight on time, please, I'd just put them in the record.

Chairman PEPPER. You go right ahead, Senator.

Senator PERCY. Maybe it would be quicker if I just run down these without any further comment.

Chairman PEPPER. Go right ahead.

Senator PERCY. The first recommendation that we make in the Foundation for Hospice and Home Care is that first we expand Crippled Children's Service to provide a comprehensive home care alternative for individuals up to 18 years of age. This comprehensive program should include federally-mandated eligibility and coverage criteria and respite care.

Second, CHAMPUS. A great program. The program should make comprehensive home care available to the children of Armed Forces personnel. It's not now available.

Third, create and fund a program of pediatric hopsice care.

Fourth, revise the medicare program to ensure home care availability for chronically ill or severely disabled individuals over the age of 18.

Fifth, provide incentives for private insurers that will encourage them to remove the institutional bias in existing health insurance policies by making home care available to chronically ill or severely disabled children. And we can do this as we know at tremendous reduction in cost to the Federal Government.

Sixth, increase education and training of medical personnel to handle the problems of our new technology and the resultant population of medically fragile children.

And seventh, increase public awareness of the availability of the home care alternative to institutionalization, which our banquet last night and dinner will continue to do.

Eighth, continue and expand research into the causes and potential cures of 11 market diseases of chronically ill children.

And finally, establish educational opportunities and programs for the burgeoning class of technology-dependent children.

Mr. Chairman, I thank you very much, and the distinguished members of your committee and again, I commend you on these hearings that will be so meaningful and important.

Chairman PEPPER. Senator, I am sure I speak for my whole committee here and the Committee on Children, Youth and Families, expressing our profound gratitude to you and Senator Moss for the magnificent statements you have given here today.

Incidentally, my plane didn't get into the airport until 9 o'clock last evening, and that is the reason I wasn't at the dinner. I'm sorry that I had to miss that happy occasion.

But your colleagues will be very much impressed, your former colleagues with whom you served with such distinction your country as well as the Congress, by the statements that you and Senator Moss have made here this morning, because they all have profound respect for you on both sides of the aisle.

So we are very grateful to you for coming here and I'm very proud to be on the board of trustees with you gentlemen. Let's keep fighting until we can make some of these wise things a reality for our country and our people.

The next witness is Dr. James Perrin, Director of the Ambulatory Care Program, Children's Service, Massachusetts General Hospital in Boston, on behalf of the American Academy of Pediatrics. Dr. Perrin.

STATEMENT OF JAMES PERRIN, M.D.

Dr. PERRIN. Thank you very much, Mr. Chairman, Mr. Miller. I am a general pediatrician practicing in the State of Massachusetts, currently on the staff of Massachusetts General, on the Harvard Faculty, and I wanted to say how honored I am to be able to be here.

Children with chronic illnesses and their families live in the twilight zone of public understanding. And your two committees are to be thanked and appreciated for helping to bring this twilight group of children in America to public knowledge and understanding.

I think we've heard this morning a clear statement that children deserve to be at home with their families. That really should be the goal of public policy and public programs as we develop them.

Many families, as we've heard this morning, currently go without adequate services because of inadequacies especially in the private health insurance market, because of inadequacies in Medicaid and how Medicaid serves families, and inadequacies in a number of other governmental programs, perhaps most strikingly the Title 5 Crippled Children's Service activities.

What are some of those problems? They're the issues of deductible payments; they're the institutional biases that we've heard; the lack of family coverage that we've heard; the issues with respect to preexisting condition waivers.

With respect to medicaid a striking fact is that if you have a chronic illness and also live below the poverty line, you are twice as likely to have neither public nor private insurance as if you lived below the poverty line without a chronic illness.

We prepared a longer statement that I think documents the variety of the issues, the scope of the problem, the number of children we're talking about, some of the things we know about costs. I'm not going to give you all those details now but would ask that that might be in the record of the hearing today.

[The prepared statement of Dr. Perrin follows:]

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PREPARED STATEMENT OF JAMES PERRIN, M.D., ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS

Introduction

Mr. Chairman, members of the committee, I am Dr. James Perrin, here today on behalf of the American Academy of Pediatrics, an organization representing more than 30,000 pediatricians who are dedicated to the promotion of maternal and child health. At the outset I want to commend you, Mr. Chairman, for convening this hearing today on children's catastrophic illness. Despite the public debate on the need for a comprehensive catastrophic health care program, no one until recently has focused on children. Little is known about the magnitude and distribution of this population. What we do know, however, is that children represent a small but important segment of the total catastrophic expense bill.

In this testimony the Academy seeks 1) to define catastrophic illness; 2) to examine unique characteristics of catastrophic illness among children vs. other age groups; 3) to develop preliminary national estimates of children at risk for incurring catastrophic medical expenses; 4) to describe the demographic, health and functional status, and insurance characteristics of these children; and 5) to review a range of policy options to reduce children's catastrophic expenses. The Academy's task force that has been reviewing this issue will complete work on specific policy recommendations involving catastrophic coverage for children within a week. Our efforts at that time will be coordinated with many of the child advocate groups represented here today -- as well as others -- to submit to you promptly a unified, comprehensive plan to provide comprehensive catastrophic health care to children.

Defining Catastrophic Illness

Catastrophic illness is typically defined in three ways:

1) total annual medical expenditures greater than a threshold amount -- e.g., $10,000 (regardless of insurance coverage) or
2) total out-of-pocket expenses in excess of a fixed amount -- e.g., $2,000 or
3) total out-of-pocket expenses as a percent of family income -- e.g., 10%-15%.

Catastrophic illness is experienced by children with and without health insurance coverage. Some families with extensive private insurance coverage exceed their catastrophic limits. Others with less generous coverage have limited benefit packages and consequently end up paying a large portion of their medical bills out of pocket. Still others have little or no private insurance coverage; they either pay for most of their care out of pocket, or obtain Medicaid, or rely on free care provided by clinics, hospitals and other health professionals. In other words, catastrophic expenses are influenced not only by the presence or absence of health insurance, but also by eligibility policies for dependents, the specific benefits that are limited or excluded, the deductible or co-insurance policies, and the catastrophic protection provisions.

Catastrophic Illness Differences Among Children vs. Adults

Children with catastrophic medical expenses have to be examined differently from adults for several reasons. Compared with Medicare beneficiaries, families with children are less likely to purchase supplemental insurance to protect themselves from financial disasters. In addition, children (as well as adults in their child-bearing years) are likelier to be uninsured or Medicaid-insured and consequently more apt to incur costs that are uncompensated. Moreover, children require more ambulatory care than hospital care; therefore the resource utilization picture for children with catastrophic expenses looks quite different from that for other age groups.

National Estimates of Children at Risk for Catastrophic Expenses

Estimating the burden of childhood catastrophic illness is complex. First, there is no single data base that collects this information. Second, existing national expenditures surveys are at least six years out of date and tend to have a relatively small number of children with catastrophic expenses. Third, many of the more current data bases include only hospital data. Fourth, few national or state surveys are population-based or longitudinal.

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With these limitations in mind, the following preliminary national estimates of children at risk for catastrophic expenses can be made from the 1980 National Medical Care Utilization and Expenditure Survey (NMCUES) (Newacheck, 1986). These figures, displayed in Tables 1 and 2, are underestimates because of the changes that have occurred since 1980 in insurance policies, including increased deductibles and copayments as well as many recent advances in the technology of newborn intensive care.

- 0.51% or 400,000 noninstitutionalized children under 19 had total medical expenses greater than $5,000.
- 0.36% or 300,000 children had out-of-pocket medical expenses greater than $2,000.
- 0.61% or 421,000 children had out-of-pocket medical expenses greater than 10% of their family's income.

Newacheck (1986) examined the characteristics of children in the top 10 percent of out-of-pocket expenses and found that adolescents aged 16-18 represent 26% of this population and children under 2 about 10.5%. Moreover, these children were four times as likely to be at least 30 days ill in bed; two times as likely to be in fair or poor health, and two times as likely to have limitations of activity.

In a 1984 study on insurance options just for chronically ill children, it was estimated that the total number of uninsured chronically ill children potentially eligible for catastrophic insurance is about 52,000. Add to that another 6,500 who have inadequate insurance protection and the total would be approximately 58,500. This represents approximately 2.7% of the noninstitutionalized child population under 19 or about 15% of all potential catastrophic-eligible children (based on the above 1980 estimates).

Based on these findings, fewer than 1 million children or under 1% of all children under 21 are likely to require some catastrophic expense relief (if defined as out-of-pocket medical expenses greater than 10% of a family's income). However, if catastrophic is defined as total annual medical expenses in excess of $10,000 (regardless of insurance coverage), 5-10% of all children might be eligible. Clearly, far more actuarial and research analysis is required to be confident about the actual size and characteristics of the infant, child and youth population, ages 0-21, at risk for incurring catastrophic expenses.

Characteristics of Children at Risk for Catastrophic Expenses

Child populations at greatest risk for incurring catastrophic expenses are:

-- by age: infants, toddlers, and adolescents;
-- by health status: birth-related conditions and chronic conditions as measured by functional limitations;
-- by socioeconomic status and health insurance coverage: children who are poor and near-poor and are uninsured all or part of the year.

The following section is primarily devoted to infants (including newborns) and chronically ill children. To present a more comprehensive picture, further information is needed on adolescents and other school-aged children. Data are provided from the National Hospital Discharge Survey (NHDS) and the California Health Facilities Commission (CHFC) on the size of the infant population at risk for catastrophic expenses (as measured by hospital lengths of stay in excess of 2 weeks), diagnosis, hospital bills per stay (in 1983), and expected source of payment.

A note of caution: these preliminary data are largely based on hospital utilization and its associated charges. With the exception of the National Medical Care Utilization and Expenditure Survey (NMCUES), no information is provided on ambulatory care. While ambulatory services are relatively inexpensive on a per-child basis, they are extremely important to factor into the estimates of catastrophic expenses, particularly for infants, toddlers, and adolescents. Moreover, it is well documented that children who are uninsured or underinsured are less likely to use preventive care services. Ambulatory care services, unlike hospital services, are often viewed as discretionary and are therefore inadequately used by families with limited or no insurance coverage. Finally, length of hospital stay is only one indicator of risk for catastrophic expenses. Many children who are hospitalized for less than two weeks also incur catastrophic expenses as do some children who, except for their birth, are not hospitalized at all.

1. Infants under 1 (including newborns)

A. National Incidence Estimates

Data from the 1984 National Hospital Discharge Survey show that 2.7% (128,132) of the 4.7 million infant (including newborns) discharges were for a period of 15+ days (Table 3). Fifty percent of these lengthy discharges

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(64,470) were for disorders relating to short gestation and unspecified low birth weight; 7.6% (9,765) were for congenital anomalies; and 5.9% (7,546) were for respiratory distress syndrome. The remaining 36.2% (46,351) infant discharges were from all other diagnoses. Roughly half of all lengthy discharges were for sick newborns and half were for sick infants. Unfortunately, it is impossible to determine from the NHDS how many infants were hospitalized and rehospitalized; only the total number of infant discharges is available.

Of the 3.9 million newborns (defined as patients admitted by birth) discharged in 1984, only 1.7% (64,099) had lengths of stay in excess of 14 days. Certain conditions originating in the perinatal period accounted for 89.8% (57,571) of these lengthy hospital stays.

B. National Insurance Estimates

Table 3 summarizes 1984 newborn data from the National Hospital Discharge Survey (NHDS) on expected principal source of payment. The NHDS does not obtain information on the actual source of payment. With the exception of the 1980 NMCUES and the 1977 NMCES data, it is impossible to determine the actual source(s) of hospital payment for children from national data bases. In addition, none of these data explains the scope of insurance coverage provided by those who are insured for all or part of the year.

The NHDS data, however, are illustrative of probable insurance sources for newborns. The reader should be cautioned about the self-pay category -- many families with newborns who incur high medical bills spend down and become eligible for Medicaid.

Of the 3.86 million newborn discharges reported in 1984 by the NHDS, 16.6% expected their source of payment to be out of pocket (self-pay); 15.4% for Medicaid; 61.2% for private insurance; and 6.6 for other remaining sources. For those 61,748 newborns with an ALOS greater than 14 days, 25.4% responded as self-pay, 22.2% as Medicaid, 42.0% as private, and 10.4% as other.

The NHDS data show that children with lengthy hospital stays are likelier than their healthier counterparts to expect to pay out of pocket or be covered by Medicaid and less likely to be privately insured. To what extent the self-pay patients actually become Medicaid recipients is unclear. Several questions can be raised about the differences in private insurance as a source of payment among all children (61.2%) as compared with children who required hospital stays greater than 14 days (42.0%). First, is the expected source of payment similar to the actual source? Second, could these large differences be accounted for by limited dependent policies, pre-existing condition clauses, and/or low catastrophic limit provisions among private insurers.

C. California Incidence and Cost Estimates

The 1983 data provided by the California Health Facilities Commission (CHFC) include approximately 511 hospitals in the state, and represent almost 10% of all infant discharges in the United States (with all children's hospitals, university and general hospitals reporting and only Kaiser patients excluded). These CHFC data are displayed in Tables 4 and 5. Table 4 summarizes the number of cases, days, ALOS, total charges, and average charge per case for all infant discharges with hospital lengths of stay greater than 16 days. Table 5 provides a ranking of each of the diagnostic categories in terms of the above variables (e.g., cases), with 1 being the highest and 21 the lowest. The following section describes some of the major characteristics of this infant population at possible risk for catastrophic illness. Note: just as with the NHDS, it is impossible to tell how many of these cases were readmissions and also how many diagnoses are chronic vs. acute.

CHFC reports 8,272 infant and newborn discharges in 1983 with lengths of stay in excess of 16 days. This represented 2.1% of all hospital discharges, yet 22.6% of all hospital days. The average length of stay (ALOS) for all infants and newborns in this 16+ category was 37.4 days, with an average charge per stay of $35,607. This contrasts sharply to the ALOS of 3.5 for all CHFC's infant discharges and the average charge per stay of $1,764. Some $294.5 million or 42.4% of all CHFC charges (amount billed) was spent on this infant population.

Three diagnostic categories -- obstetric, perinatal conditions, and congenital anomalies, accounted for 83% of the cases with lengthy hospital stays and approximately 20% of all hospital days. Fifty percent of these lengthy discharges were for sick newborns and the other 50% were for sick infants. Similar to the NHDS estimates, 1.2% or 4,173 newborn discharges had hospital stays greater than 16 days.

Examining diagnostic categories with the largest number of cases presents only part of the picture. It is also important to examine each diagnostic group in terms of its probability of falling into the lengthy discharge group. The three diagnostic categories likeliest to have lengthy hospital stays were 1) infants with a discharge diagnosis of musculoskeletal system and connective tissue diseases with a 23% likelihood of falling into this high-cost (16+ day) group; 2) infants with mental disorders with a 17% chance; and 3) infants with

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perinatal conditions with a 16% probability of spending at least 16 days in hospital.

Average lengths of stay by diagnostic category for this high-cost group, displayed in Table 4, show that diagnoses with the longest lengths of stay were: 1) mental disorders (45 days), 2) perinatal conditions (42.6 days), and 3) endocrine, nutritional and metabolic diseases and immunity disorders (41.3 days).

Three diagnostic groups accounted for 86% (or $254.6 million of a total of $294.5 million) of the total charges among this 16+ hospital day infant population group: birth and pregnancy ($132.5 million), perinatal conditions ($90.8 million), and congenital anomalies ($31.3 million).

The infant cases with the most expensive cost per stay in 1983 were congenital anomalies ($45,280), certain conditions originating in the perinatal period ($5,037), and neoplasms ($40,402). For more information about disease-specific incidence and cost figures, see Tables 4 and 5.

2. Newborn Intensive Care and Low Birthweight Cost Estimates

A. Estimated Costs of Newborn Intensive Care, 1985

Based on 1978 data, newborn intensive care costs in 1985 totaled $2.4-$3.3 billion and averaged $14,698 for each infant. Using the same assumptions, but updated using 1985 live birth figures from the National Center for Health Statistics and the 1985 medical care component of the Consumer Price Index, the following total and average estimates of the costs of newborn intensive care can be made:

Total Newborn Intensive Care Costs, 1985: $2.4-$3.3 billion

Calculations:

Number of births (3,749,000)	X	Percentage of all births admitted to NICUs (0.06)	X	Mean cost/ patient ($14,698)	=	TOTAL COST	$3.31 billion
No. of Level III beds reported by Ross Labs (7,387)	X	Estimated Occupancy Rate (0.90)	X	Days/ Year (365)	X	Mean cost/ ($1,001)	= TOTAL COST $2.43 billion

Average Newborn Intensive Care Costs, 1985: $14,698

B. Estimated Hospitalization Costs for LBW Infants during their First Year of Life, 1985

In 1985 hospitalizations costs for LBW infants in their first year of life totaled $3.1 billion. For LBW infants hospitalized only at birth, the initial hospitalization costs averaged $10,062. And, for those LBW infants who were re-hospitalized, the total first year of life charges were approximately $20,528. This information is based to some extent on the Institute of Medicine's 1985 report, Preventing Low Birthweight (Chapter 10: Prenatal Care and Low Birthweight: Effects on Health Care Expenditures).

1. Low Birthweight (LBW) Rate: 6.8

This is 1983 data from the National Center for Health Statistics, the latest year for which data are available. Note: 1.2% of all births are very low birthweight (under 1,500 grams or less than 3 lbs. 4 oz.) and 5.6% weigh between 1,501 and 2,500 grams (between 3 lbs. 4 oz. and 5 lbs. 8 oz.).

2. Number of LBW Infants: 254,932

(.068 X 3,749,000)

3. Estimated Mortality among LBW Infants: 8% or 20,395

(.08 X 254,932)

4. LBW Survivors: 234,537

(254,932 - 20,395)

5. **Initial Total Hospitalization Costs: $2,565,125,784**

   (13 days X $774 X 254,932)

   The average length of stay for LBW is 13 days according to the 1984 NHDS. Unfortunately, it was impossible with the NHDS data to obtain length-of-stay information for very low birthweight and moderate low birthweight, assuming infants under 1,500 grams would have to be hospitalized for longer stays. The average charge per day in children's hospitals, according to the American Hospital Association's data, is $774 in 1985.

6. **Initial Average Hospitalization Costs: $10,062**

   ($2,565,125,784 - 254,932)

7. **Number of LBW Infants Rehospitalized: 51,768**

   (.383 X 37,340) + (.19 X 197,197)

   According to McCormick et al, 38.3% (or 14,301) of all very low birthweight infants (less than 1,500 g) are likely to be rehospitalized for an average length of stay (ALOS) of 16.2 days, and 19% (or 37,467) of moderately low birthweight infants (greater than 1,500 g and less than 2,500 g) are likely to be hospitalized for an ALOS of 12.5 days.

8. **Total Rehospitalization Costs: $541,810,604**

   (16.2 X $774 X 14,301) + (12.5 X $774 X 37,467)

9. **Average Rehospitalization Charges: $10,466**

   ($41,810,604 - 51,768)

10. **Total First Year of Life Hospital Charges for All LBW Infants: $3,106,936,388**

    ($2,565,125,784 + $541,810,604)

11. **Average First Year of Life Hospital Charges for LBW Infants who were Rehospitalized: $20,528**

    ($10,062 + $10,466)

3. Chronically Ill Children

The following data are abstracted from the 1980 National Medical Care Utilization and Expenditure Survey and the 1980 Census of Persons in Institutions and other Group Quarters. This information profiles chronically ill children in terms of a continuum of functional limitations and the degree to which they might be at risk for catastrophic medical expenses (in terms of total annual medical expenditures greater than $10,000, regardless of insurance coverage).

Approximately 185,000 institutionalized children and noninstitutionalized children with major limitations of activity (under 18) would most likely incur catastrophic expenses. However, it is unclear how many children with chronic conditions that result in moderate, mild or no limitations of activity might also fall into this category. Similarly, we do not know how many children without chronic conditions but with an acute illness or injury would have an extraordinary medical bill in any given year.

Childhood chronic conditions can be described along a continuum. At the most severe end are the 70,000 children under 18 who resided in institutions and other group quarters in 1980. While diagnostic information on these high-cost children is unavailable, it appears from the types of facilities they live in that mental conditions are the main reason for institutional placement. Each of these children can be classified as having catastrophic expenses in terms of total medical expenditures, regardless of insurance coverage.

At the next level are children restricted in their major activity (for school-age children, this means unable to attend school; for pre-school children, this means inability to engage in any kind of play). According to the National Health Interview Survey in 1980, 75,000 children under 17 were limited in their major activity. Children under six were four times as likely to fall into this category. Approximately 25% of these children suffer with impairments of speech, special sense and intelligence as well as an assortment of other mental and nervous system disorders. The other 75% have a variety of physical conditions, with paralysis and deformities of the body accounting for a significant portion. It is highly likely that most of these children would incur extraordinary medical expenses in a given year. For how many consecutive years catastrophic expenses might be expected is unclear.

The third group along the continuum is children with chronic conditions who are able to attend school or play, but are limited in the kind or amount of activity (e.g., attending school part time). The 1980 NHIS data show that 1.1 million children under 17 fall into this category, with almost a 50/50 distribution among children under and over age six. Almost one-third of these children suffer from speech, special sense and intelligence impairments and a variety of other mental and nervous system disorders. Another two-thirds of children have a range of physical diseases and impairments, with respiratory diseases and asthma in particular affecting the largest number. It is unclear what portion of these children would have catastrophic expenses.

Further down this continuum are chronically ill chilgren who can attend all normal school activities but are limited in their outside-school activities (Note: only school-age children fall into this group). More than one million children fall into this category, with a similar diagnostic picture as described in the previous paragraph, with lower prevalence rates of mentally handicapped conditions and higher prevalence rates of orthopedic impairments and deformities. No information is available on how many of these children incur very high annual medical bills.

Finally, it is estimated that approximately 11 million children have one or more chronic conditions but suffer no long-term disability. The majority of conditions reported in this group are respiratory. No information is available on their risk for incurring catastrophic expenses.

Chronically ill children with limitations of activity are at increased risk for catastrophic illness because of their relatively high utilization of a broad range of health services, as described in Table 6 and summarized below.

- Approximately 8% of children with chronic conditions have functional limitations. These children (with LA) are twice as likely to be hospitalized and spend four times as many days in hospital as children with no LA.
- Children with LA visit physicians twice as often and are twice as likely to make five or more physician visits over a year's time.
- Children with LA see non-physicians five times as often as non-LA children and, at the same time, are four times as likely to have five or more visits.
- Activity-limited children receive twice the number of prescription medicines and twice the number of medical supplies and equipment as non-LA children.
- While children with LA make up only 4% of the population, they account for 11% of total child health expenditures.
- Children with LA have twice the out-of-pocket expenses as do non-LA children.

Conclusions

Families with children who experience a catastrophic illness -- at birth, in childhood, and/or in adolescence -- are often placed in extreme financial indebtedness. Many families exhaust their private insurance benefits and in order to qualify for Medicaid have to spend down their assets to such a degree that, once eligible, they become virtually impoverished. Other families covered by Medicaid are often put into untenable positions because the state often places severe limits on the amount of care that will be reimbursed (through waivers) or on the number of mandatory and optional services. While state Crippled Children's Services and other private foundations (e.g., Shriner's and the Muscular Dystrophy Association) play a critical role as payers of last resort, the inconsistencies by state, by childhood condition, and by family's income are extremely arbitrary.

To reduce some of these state variations in order to insure more consistent public and private catastrophic policies requires further examination of:

1) Mandatory adoption of medically needy programs under Medicaid and more generous spend-down policies for poor and near-poor families with children.

2) Expansion of Medicaid home and community-based waiver programs, not solely based on cost-effectiveness, for families with medically fragile children.

3) Increased coordination and supplementing of Medicaid with EPSDT benefits, specifically designed for chronically ill children and other children with acute but catastrophic illness.

4) Exclusion of pre-existing condition clauses.

5) Expansion of public and private insurance policies for adolescents and young adults between the ages of 18-25.

Many policy options are currently being considered (and have been adopted in a growing number of states) which hold promise for reducing the family's,

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provider's and insurer's risk in care for children with catastrophic illness. Included are:

1. State-mandated high risk pools

The state requires all insurers to establish a pool to cover those individuals who are uninsurable because of a prior existing chronic medial condition. The pool would offer comprehensive coverage at reasonable premium rates to be paid for by the family (or subsidized through other mechanisms). Actual losses or profits would be shared equitably by the insurers in the pool.

2. Employee mandates

Require employers to provide minimum insurance which covers prenatal services and primary services for children, with insurance pools to assist small employers.

3. Medicaid expansions

As discussed previously, mandate Medicaid coverage for pregnant women and children who are below the federal poverty level and standardize Medicaid coverage for mandated services.

4. Expand Title V MCH-CC programs

Obviously these options will need to be examined with an eye for children's unique needs. For example, although risk pools may help a number of children, as currently established these mechanisms have failed the pediatric population. And, while there is much merit to Medicaid expansions and employee mandates, each has limitations. We look forward to working closely with you, other child advocates, and provider organizations to develop a comprehensive proposal to meet the needs of all children who insur catastrophic expenses.

TABLE 1

TOTAL CHARGE AND OUT-OF-POCKET EXPENSE DISTRIBUTION
FOR CHILDREN 0 TO 18 YEARS: U.S., 1980

Charge Level at or Above	Percent with Total Charges (incl. dental) at or above threshold	Total Number of Persons (millions)	Percent with Out-of-Pocket (incl. dental) at or above threshold	Total No. of Persons (millions)
$ 500	13.49%	9.4	4.46%	3.1
1,000	7.61	5.3	1.96	1.4
1,500	4.52	3.31	0.81	0.6
2,000	2.69	1.9	0.36	0.3
2,500	1.59	1.1	0.15*	0.1*
5,000	0.51	0.4	0.05*	0.03*
7,500	0.28	0.2		
10,000	0.17*	0.1*		

* May be statistically unreliable due to small sample size.

Note: All figures in 1980 dollars; excludes institutionalized populations; estimates based on person time-adjusted weight.

Source: Unpublished provisional data from microdata tapes, 1980 National Medical Care Utilization and Expenditure Survey.

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TABLE 2

OUT-OF-POCKET MEDICAL CARE EXPENDITURES (INCLUDING DENTAL) FOR CHILDREN WITH OUT-OF-POCKET EXPENSES OF $500 OR MORE, AS A PERCENT OF FAMILY INCOME FOR CHILDREN 0 TO 18 YEARS: U.S., 1980

Children with Out-of-Pocket Expenses at or Above	Estimated No. of Children (thousands)	Percent of All Children
10%	421	0.60%
15	270	0.39
20	198	0.28
25	187	0.27
30	157	0.22
50	81	0.12*

* May be statistically unreliable due to small sample size.

Note: All figures in 1980 dollars; excludes institutionalized populations; estimates based on person time-adjusted weight.

Source: Unpublished provisional data from microdata tapes, 1980 National Medical Care Utilization and Expenditures Survey.

TABLE 3

EXPECTED PRINCIPAL SOURCE OF PAYMENT FOR HOSPITALIZATION FOR ALL NEWBORNS AND NEWBORNS WITH LENGTHS OF STAY GREATER THAN 14 DAYS: UNITED STATES, 1984

Newborns	All Sources of Payment	Self-Pay	Medicaid	Private Insurance	Other
Total	3,857,445	640,257	603,305	2,360,004	253,879
	100.0	16.6	15.6	61.2	6.6
Greater than 14 days	61,744	15,666	13,738	25,913	6,427
	100.0	25.4	22.2	42.0	10.4

Source: Unpublished data from the National Hospital Discharge Survey, National Center for Health Statistics.

TABLE 4

PREGNANCY, BIRTH & INFANT (UNDER 1) HOSPITALIZATIONS IN CALIFORNIA*, BY DIAGNOSES: CASES, DAYS, AND CHARGES: CY 1983

DIAGNOSES	CASES	DAYS	ALOS	TOTAL CHARGES	AVG. CHARGE PER CASE
ALL CASES					
Number	393,732	1,371,939	3.5	$694,668,459	$ 1,764
Percent	100.0	100.0		100.0	
ALL CASES WITH LENGTHS OF STAY OF 16+ DAYS					
Number	8,272	309,492	37.4	$294,537,187	$35,607
Percent	2.1	22.6		42.4	
1. INFECTIONS					
Total Number	5,355	25,421	4.7	$16,956,351	$ 3,166
Percent	100.0	100.0		100.0	
Number with 16+	157	4,431	28.2	$ 4,010,433	$25,601
Percent	2.9	17.4		23.7	
2. NEOPLASMS					
Total Number	442	3,148	7.1	$ 3,523,441	$ 7,972
Percent	100.0	100.0		100.0	
Number with 16+	45	1,498	33.3	$ 1,818,093	$40,402
Percent	10.2	47.6		51.6	
3. ENDOCRINE, NUTRITIONAL AND METABOLIC DISEASES AND IMMUNITY DISORDERS					
Total Number	767	5,738	7.7	$ 4,386,449	$ 5,872
Percent	100.0	100.0		100.0	
Number with 16+	69	2,848	41.3	$ 2,028,871	$29,392
Percent	9.2	49.6		46.2	
4. DISEASES OF THE BLOOD AND BLOOD FORMING ORGANS					
Total Number	249	995	4.0	$ 743,582	$ 2,986
Percent	100.0	100.0		100.0	
Number with 16+	8	213	26.6	$ 177,211	$22,151
Percent	3.2	21.4		23.8	
5. MENTAL DISORDERS					
Total Number	78	341	10.9	$ 318,425	$ 4,082
Percent	100.0	100.0		100.0	
Number with 16+	13	585	45.0	$ 173,424	$13,340
Percent	16.7	69.8		54.5	
6. DISEASES OF THE NERVOUS SYSTEM AND SENSE ORGANS					
Total Number	2,988	18,101	6.1	$14,575,134	$ 4,877
Percent	100.0	100.0		100.0	
Number with 16+	216	6,326	29.6	$ 6,148,727	$28,752
Percent	7.2	34.9		42.2	
7. DISEASES OF THE CIRCULATORY SYSTEM					
Total Number	548	3,957	7.2	$ 4,172,605	$ 7,727
Percent	100.0	100.0		100.0	
Number with 16+	50	1,567	31.3	$ 1,788,099	$35,762
Percent	9.3	39.6		42.9	
8. DISEASES OF THE RESPIRATORY SYSTEM					
Total Number	13,206	55,489	4.2	$38,463,160	$ 2,913
Percent	100.0	100.0		100.0	
Number with 16+	218	5,441	25.0	$ 5,477,963	$25,128
Percent	1.7	9.8		14.2	
9. DISEASES OF THE DIGESTIVE SYSTEM					
Total Number	6,882	27,030	4.0	$19,413,838	$ 2,821
Percent	100.0	100.0		100.0	
Number with 16+	173	6,149	35.5	$ 5,502,564	$31,807
Percent	2.5	22.1		28.3	
10. DISEASES OF THE GENITOURINARY SYSTEM					
Total Number	846	3,993	4.7	$ 3,054,606	$ 3,611
Percent	100.0	100.0		100.0	
Number with 16+	20	576	28.8	$ 757,444	$37,872
Percent	2.4	14.4		24.5	
11. COMPLICATIONS OF PREGNANCY, CHILD BIRTH AND PUERPERIUM					
Total Number	48	123	3.1	$ 92,124	$ 2,303
Percent	100.0	100.0		100.0	
Number with 16+	0	0	0	$ 0	$ 0
Percent	0.0	0.0		0.0	

* All payers except those reporting no charge (Kaiser).

DIAGNOSES (Cont.)	CASES	DAYS	ALOS*	TOTAL CHARGES	AVG. CHARGE PER CASE
12. DISEASES OF THE SKIN AND SUBCUTANEOUS TISSUE					
Total Number	678	3,102	4.6	$ 1,862,423	$ 2,747
Percent	100.0	100.0		100.0	
Number with 10+	13	251	22.8	$ 200,813	$18,256
Percent	1.8	8.1		10.8	
13. DISEASES OF THE MUSCULOSKELTAL SYSTEM AND CONNECTIVE TISSUE					
Total Number	259	2,362	9.2	$ 1,472,306	$ 5,707
Percent	100.0	100.0		100.0	
Number with 10+	58	1,310	22.6	$ 774,916	$13,361
Percent	22.5	55.5		52.6	
14. CONGENITAL ANOMALIES					
Total Number	5,709	47,673	8.4	$59,068,040	$10,348
Percent	100.0	100.0		100.0	
Number with 10+	691	26,311	38.1	$31,288,497	$45,280
Percent	12.1	55.2			
15. CERTAIN CONG.TIONS ORIGINATING IN THE PERINATAL PERIOD					
Total Number	12,639	128,274	10.1	$130,796,575	$10,349
Percent	100.0	100.0		100.0	
Total with 10+	2,017	85,843	42.6	$90,840,575	$45,037
Percent	16.0	66.9		69.5	
16. SYMPTOMS, SIGNS AND ILL-DEFINED CONDITIONS					
Total Number	3,684	15,279	4.1	$10,165,844	$ 2,759
Percent	100.0	100.0		100.0	
Total with 10+	98	2,968	30.3	$ 2,338,734	$23,865
Percent	2.7	19.4		23.0	
17. INJURIES					
Total Number	1,575	6,452	4.1	$ 5,029,736	$ 3,193
Percent	100.0	100.0		100.0	
Total with 10+	88	2,167	24.6	$ 1,808,305	$20,549
Percent	5.6	33.6		36.0	
18. POISONING					
Total Number	856	5,276	6.2	$ 5,543,123	$ 6,476
Percent	100.0	100.0		100.0	
Total with 10+	73	2,520	34.5	$ 2,873,156	$39,358
Percent	8.5	47.8		51.8	
19. V CODES: BIRTH AND PREGNANCY					
Total Number	335,521	1,009,148	3.0	$367,268,700	$ 1,095
Percent	100.0	100.0		100.0	
Total with 10+	4,173	154,883	37.0	$132,484,334	$31,748
Percent	1.2	15.3		36.1	
20. OTHER V CODES					
Total Number	542	2,304	4.3	$ 1,659,500	$ 3,062
Percent	100.0	100.0		100.0	
Total with 10+	24	737	30.7	$ 486,936	$20,289
Percent	4.4	32.0		29.3	
21. NONE OF THE ABOVE					
Total Number	898	6,531	7.3	$ 6,102,025	$ 6,795
Percent	100.0	100.0		100.0	
Total with 10+	72	3,148	43.7	$ 3,222,585	$44,758
Percent	8.0	48.2		52.8	

SOURCE: Unpublished data from the California Association of Children's Hospitals, 1983. Prepared for the American Academy of Pediatrics by Jonathan Bates and Susan Meister of San Diego Children's Hospital and Health Center, May 8, 1986.

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TABLE 5

RANKING* OF DISEASES WITH LENGTHS OF STAY GREATER THAN 16 DAYS BY NUMBER AND DISTRIBUTION OF CASES AND DAYS, AVERAGE LENGTH OF STAY, TOTAL AMOUNT AND DISTRIBUTION OF CHARGES, AND AVERAGE CHARGE PER CASE; CACH, 1983

DIAGNOSES	TOTAL CASES	%	TOTAL DAYS	%	ALOS	TOTAL CHGS.	%	AVG. CHG.
ALL CASES WITH LOS > 16 DAYS	8,272	2.1	309,492	22.6	37.4	$294.58	42.4	$35,607
RANGE (low to high)	8 to 4,173	1.2 to 22.5	213 to 154,603	8.1 to 69.6	22.0 to 45.0	$173 to 132.58	10.1 to 69.5	$13,140 to 45,280
1. Infections	7	14	7	16	14	7	17	12
2. Neoplasms	15	5	14	8	9	12	4	6
3. Endocr./Metab. Immunity	12	7	10	5	4	11	8	10
4. Blood Diseases	20	13	20	14	15	19	16	15
5. Mental Disorders	18	2	17	1	1	20	2	20
6. CNS & Sense Organs	5	9	6	6	16	6	10	11
7. Circulatory Sys	14	6	13	9	10	14	9	7
8. Respiratory Sys	6	10	6	10	17	8	10	13
9. Gastrointest. Sys	8	16	5	13	7	9	14	8
10. Genitourin. Sys	17	17	18	18	13	16	15	9
11. Obstetric	21	21	21	21	21	21	21	21
12. Skin Diseases	19	19	19	20	19	18	20	18
13. Musculskel/Connect Tiss	13	1	15	3	20	15	5	19
14. Congenital Anomalies	3	4	3	4	5	3	3	1
15. Perinatal Conditions	2	3	2	2	3	2	1	2
16. Signs & Symptoms	8	15	9	15	12	10	18	14
17. Injuries	9	11	12	11	18	13	12	16
18. Poisonings	10	8	11	7	8	9	6	5
19. V Codes: Birth & Preg	1	20	1	17	6	1	11	9
20. Other V Codes	16	12	16	12	11	17	13	17
21. None of the Above	11	9	8	6	2	8	4	3

* Highest = 1
Lowest = 21

SOURCE: Unpublished data from the California Association of Children's Hospitals, 1983. Prepared for the American Academy of Pediatrics by Jonathan Oaten and Susan Meister of the San Diego Children's Hospital and Health Center, May 8, 1986.

TABLE 6

CHILDREN UNDER 21 WITH AND WITHOUT LIMITATIONS OF ACTIVITY: PERCENT DISTRIBUTION OF PREVALENCE, USE OF HEALTH SERVICES, EXPENDITURES, AND INSURANCE, 1980

I. Prevalence

Not limited	96.0%
Limited	4.0

II. Use of Selected Health Services

A. Hospital Days

	0 (days)	1-7 (days)	8+ (days)
Not limited	92.3	6.9	0.8
Limited	82.0	14.5	3.5

B. Physician Visits

	0 (visits)	5+ (visits)
Not limited	26.6	19.3
Limited	14.2	38.9

* Updated using the medical care component of the CPI.

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	0 (visits)	5+ (visits)
C. Non-Physician Visits		
Not limited	70.8	3.4
Limited	56.8	13.1
	0 (medic)	3+ (medic)
D. Prescription Medications		
Not limited	44.6	13.4
Limited	36.8	25.8
	0 (svcs)	3+ (svcs)
E. Other Medical Services (Supplies, equipment)		
Not limited	88.3	0.6
Limited	78.9	5.7

III. Expenditures	1980	1 985*
A. Total Charges		
Not limited	$763	$199
Limited	760	1,152
B. Out-of-Pocket Expenses	1980	1985
Not limited	76	115
Limited	135	205

IV. Insurance

	Full Year	Part Year
A. Type of Coverage		
1. Medicaid		
Not limited	10.9	5.1*
Limited	16.3	9.7
2. Other Public Insurance		
Not limited	1.3	4.2
Limited	1.9	5.7
3. Private Insurance		
Not limited	63.1	14.2
Limited	59.3	15.5

4. Combined Coverage (Medicaid, other public, and/or private coverage for all or part year)

Not limited	90.1
Limited	92.0

B. Period of Coverage

	Total	All Year	Part Year	None
Not limited	100.0	76.4	14.9	8.6
Limited	100.0	77.1	16.3	6.6

Source: Abstracted from reports prepared by Paul Newacheck for the National Maternal and Child Health Resource Center as part of a National Report on Future Directions of Public Services for Children with Specialized Health Care Needs, 1986.

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Dr. PERRIN. In broad terms, let me share with you two or three facts about the epidemiology and background of long-term illness.

As was said a few moments ago, probably 10 to 15 percent of children in America have some kind of chronic health impairment. Of that number, however, only about 10 percent, or 1 to 2 percent of children in America, have severe health impairments that interfere on a regular daily basis with their being able to do the things other children do—go to school, do their chores, play with their classmates, and so forth.

That number has probably doubled in the past two decades. I believe we have gone from 1 percent of children to 2 percent of children with severe long-term illness.

That doubling has been the result of significant improvements in medical and surgical technology and in our ability as a Nation to get services to children and families.

That number is not likely to double again in the next two decades. We probably have a relatively stable population of children with severe, long-term illnesses.

And as we've seen this morning, the vast majority of those children today live to adulthood. The challenge now is how to help these children grow to be effective adult participants in our society.

In years past, we said basically that children with cystic fibrosis all died. We needn't worry about them. Children with leukemia all died. We don't have to have any special programs for them.

Children never became respirator dependent because we didn't know how to do that. They all died. We didn't have to worry about schooling for those children.

Well, times have changed. Most children with severe long-term illnesses now survive into their third decade and longer, and we have an important and exciting challenge ahead of us.

Catastrophic health insurance can be meaningful to many families. But it is important to recognize that the needs of families are complex and go well beyond traditional medical and surgical care.

Mr. Pepper made that comment a few moments ago, and I believe he is absolutely right on the target. The needs of families are broad. Insurance alone is necessary but not sufficient. Children with long-term illnesses and their families need access at least to six main groups of services.

One, high quality medical and surgical specialty care. Two, high quality general pediatric or general health services. And it's sad that these children lack the basic modicums of immunizations, health supervision, that most children in America do get.

Third, nursing services to help children be able to stay at home, to be at home, and to receive care primarily from their families. I am a so-called primary caretaker. That's what you call physicians of my ilk these days. I don't take care of children. I consult with families who do the daily care of their child. That's what you heard this morning.

We want to find ways to maximize the ability of families to be able to take care of their children.

The fourth service is preventive mental health services. The families of these children face tremendous burdens, demands on their lives and their psyches, trying to raise these children.

The fifth group of services are social services.

And the sixth and probably most neglected are educational services so these children can continue to survive well with their classmates in school. I could spend an hour talking with you about the problems that children with illness have in schools. They're interesting, problematic, and we have major steps to take forward there.

Catastrophic health insurance will help with some but not all. Attention to a child's malfunctioning knee may make the child's knee work better. But without proper habilitation, he may not walk, he may not stay up to speed with his classmates in school and he may not have access to needed appliances to improve his mobility.

So my first recommendation on catastrophic insurance is, it needs to go beyond health.

The second is, that catastrophic health insurance has the risk of being inflationary, by providing an incentive to spend up to a deductible limit after which services are free. And therefore, I would strongly recommend that developments in catastrophic health insurance be tied to incentives to build high quality, long term care programs that decrease reliance on expensive in-hospital care.

And my third and final broad recommendation is——

Chairman MILLER. What was your second one again?

Dr. PERRIN. The first is that we can't do just insurance, Mr. Miller. It's got to be broader than that.

The second is, you've got to tie an insurance program to incentives to build long-term care programs that diminish reliance on inpatient services. It can't be just insurance. It's essentially repeating the same comment in a different way.

And the third is, as you listen to the stories around the table this morning, these aren't short-term catastrophes. Very little, for adults by the way as well as children, is short-term, acute catastrophes.

We're mainly talking about long-term catastrophies. For these children, we need to have deductible periods or the equivalent that can be lifetime deductibles or 5 year deductibles and not based on a single point in time.

While our statement has gone into a series of other options, we in fact are working with some of the other people you have heard from today and hope to have a series of more explicit recommendations for you within a week, that we will hope to share with you.

Thank you very much.

Chairman MILLER. Thank you very much. Dr. Northway.

STATEMENT OF J.D. NORTHWAY, M.D.

Dr. NORTHWAY. Thank you, Mr. Chairman. I am likewise honored to be before you today.

I am J.D. Northway, the President and Chief Executive Officer of Valley Children's Hospital in Fresno, California. I am a pediatrician and pediatric nephrologist by training. The children's hospital which I administer is in rural central California, and over 60 percent of the patients which we serve are Medicaid recipients.

I am here today to speak on behalf of the Western Association of Children's Hospitals on the very critical issue of catastrophic illness among children. We commend, as have others, the select com-

mittee for its efforts to draw national attention to this issue and to develop remedies through which this crisis might be resolved.

Every year, many Americans face the trauma of a catastrophic illness in their family. All too often, that family member is a child, so the emotional devastation is compounded by the overwhelming financial burden. We've heard that over and over again this morning. Medical bills, which can run into the hundreds of thousands of dollars, can precipitate financial ruin of families without insurance or with inadequate coverage. Fortunately, however, the incidence of severe catastrophic illness in children is actually quite low. We have compiled a data base based upon our experience in California.

During 1984, there were about 500,000 children hospitalized in California. This constitutes about approximately 10 percent of the State's children. Less than 3,000 of the 500,000 of these hospitalized children incurred charges in excess of $50,000. But the total of this small group represents 22 percent of the total charges of all 500,000 children. The average cost per child in this group was over $100,000.

Who is paying these bills? Insurance coverage in this country is, as you know, quite variable. Approximately 70 percent of this Nation's children have some form of private family health insurance. Another 12 percent are covered by government-sponsored health insurance, primarily Medicaid, which varies widely across the States in terms of benefits and eligibility requirements; 19 percent or 10.2 million of this nation's children have no health insurance coverage at all—despite the fact that 50 percent of these children come from families with working parents.

Thus, in my opinion, the real victims of catastrophic health episodes are children of the working poor. These are the families whose income is in excess of medicaid eligibility levels but who do not have access to or cannot afford private health insurance. Premiums for these families can reach out-of-pocket expenses of two to three hundred dollars a month which would represent somewhere between 35 and 50 percent of the gross monthly salary of a minimum wage worker. The situation then becomes either milk or health insurance.

In addition to the children of the working poor, there are children who are simply uninsurable. And you saw a large number of those this morning. Typically, these children have preexisting medical conditions which prevent their being able to obtain private insurance coverage. These are children with cancer, cystic fybrosis and other chronic disorders. According to a 1986 national survey, approximately 31 percent of employers offering group health coverage restrict such coverage for preexisting conditions.

Another group of children——

Chairman PEPPER. Restrict what?

Dr. NORTHWAY. About 31 percent of employers offering group health coverage restrict such coverage for preexisting conditions. In other words, if a child has a preexisting medical condition, they won't insure them.

Another group of children deserving our attention are the underinsured. Underinsured families are those whose policies restrict the number of hospital days covered, cap the total dollars payable for

the insured's lifetime health care costs, or which have no maximum out of pocket limits.

How does inadequate insurance coverage affect the government? In California, of those children whose hospital bills were $5,000 or less, Medicaid paid approximately one third and the private insurers about 50 percent. For the catastrophic cases, those in excess of $50,000, Medicaid's share rose to almost 40 percent, whereas the private insurers' share dropped to 32 percent. Underinsured or uninsured families can usually deal with minor health problems. But when a catastrophe hits and the family's resources are rapidly exhausted, the already overburdened public assistance programs or the hospital providers are asked to pick up the tab.

Which hospitals typically undertake this task of caring for these children? Seventy-five percent of the children in California whose hospital bills were over $100,000 were cared for at a children's hospital or a university medical center. We believe that this is where they should be cared for. But we agonize for these families as their resources are eaten up and their dreams for the future are turned into nightmares. None of us at the Children's Hospital close our doors to these children. But the demands on our resources are many and the availability of our resources is limited.

However, if the financial risk for the cost of hospital care for all of the pediatric cases in California—over $50,000—was spread across the entire pediatric population of California, the cost would be roughly $4.55 per child per month. This amounts to less than one third of the cost of providing one day of elementary school per child.

The issue of dealing with catastrophic illnesses in children is complex and may well defy a single, short term resolution. However, it is imperative that a plan for protecting these families from economic and emotional ruin of catastrophic illness be developed.

We stand ready to support this committee's endeavors. We would suggest that any catastrophic health insurance plan for children include the following:

One, that all of this Nation's children must be provided with health insurance.

Two, that the financial risk for this coverage must be spread throughout the population so that the burden will not fall disproportionately upon any one segment.

And third, that strong case management requirements are included in order to ensure that financial resources are expended in the most effective and efficient manner.

Thank you very much.

[The prepared statement of J.D. Northway, M.D., follows:]

PREPARED STATEMENT OF J.D. NORTHWAY, M.D., PRESIDENT AND CHIEF EXECUTIVE OFFICER, VALLEY CHILDREN'S HOSPITAL, FRESNO, CA, ON BEHALF OF WESTERN ASSOCIATION OF CHILDREN'S HOSPITALS

Mr. Chairman and Members of the Committee.

Good morning. I am J. D. Northway, President and CEO of Valley Children's Hospital in Fresno, California. I am a Pediatrician and Pediatric Nephrologist by training. The children's hospital which I administer is in rural Central California. Over 60% of the patients which we serve are Medicaid recipients.

I am here today to speak on behalf of the Western Association of Children's Hospitals on the very critical issue of catastrophic illness among children. We commend the Select Committee for its efforts to draw national attention to this issue and to develop remedies through which this crisis might be resolved.

Every year, many Americans face the trauma of a catastrophic illness within their family. All too often, that family member is a child and the emotional devastation is compounded by an overwhelming financial burden. Medical bills which can run into the hundreds of thousands of dollars can precipitate the financial ruin of families without insurance or with inadequate coverage.

Fortunately, the incidence of severe catastrophic illness in children is actually very low. We have compiled data based upon the experience in California.

During 1984, there were about five hundred thousand children hospitalized in California. This constitutes approximately 10% of the state's children. Less than 3,000 of these hospitalized children incurred charges in excess of $50,000, but the total cost of this small group was in excess of $280 million and represents 22% of the total charges for all five hundred thousand plus admissions. The average cost per child in this group was over $100,000.

Who is paying these bills? Insurance coverage in this country is quite variable. Approximately 70% of this nation's children have some form of private family health insurance.

Another 12% are covered by government-sponsored health insurance, primarily Medicaid which varies widely across the states in terms of benefits and eligibility requirements. 19%, or 10.2 million, of this nation's children have no health insurance coverage at all.

Thus, the real victims of a catastrophic health episode are children of the working poor. These are the families whose income is in excess of Medicaid eligibility levels but who did not have access to, or cannot afford, private health insurance. Premiums for these families can reach out-of-pocket expenses of $200-300 per month, which would represent 35-50% of the gross monthly salary of a minimum wage worker. The situation then becomes either milk or health insurance.

In addition to the children of the working poor, there are the children who are simply "uninsurable". Typically, these children have "pre-existing" medical conditions which prevent their being able to obtain private insurance coverage; these are

children with cancer, cystic fibrosis, and other chronic disorders. According to a 1986 National survey, 31% of employers offering group health coverage restrict such coverage for pre-existing conditions.

Another group of children deserving of our attention is the underinsured. Underinsured families are those whose policies restrict the number of hospital days covered, cap the total dollars payable for the insured's lifetime health care costs, or which have no maximum out-of-pocket limits.

How does inadequate insurance coverage affects the government? In California, of those children whose hospital bills were $5,000 or less, Medicaid paid one-third and the private insurers about 1/2. For the catastrophic cases, those in excess of $50,000, Medicaid's share rose to almost 40% of the bills, whereas the private insurance groups share dropped to 32%. Underinsured or uninsured families can deal with minor health problems, but when a catastrophy hits and the family's resources are exhausted, the already overburdened public assistance programs or the hospital providers are asked to pick up the tab. 75% of the children whose hospital bills are over $100,000 are cared for at a children's hospital or university medical center. We believe that this is where they should be cared for, but we agonize with these families as their resources are eaten up and their dreams for the future turn into nightmares. None of us at the children's hospitals close our doors to these children, but the demands on our resources are many and the availability of our resources is limited. If the financial risk for the cost of

hospital care for all of the cases over $50,000 was spread across the entire pediatric population of California, the cost would be roughly $4.55/child/month. This amounts to less than 1/3 of the cost of providing one day of school for one child.

The issue of dealing with catastrophic illness in children is complex and may well defy a single short-term resolution. However, it is imperative that a plan for protecting these families from economic and emotional ruin of catastrophic illness be developed.

We stand ready to support this Committee's endeavors. We would suggest that any catastrophic health insurance plan for children include the following:

1. That all of this nation's children must be provided with health insurance.

2. That the financial risk for this coverage must be spread throughout the population so that the burden will not fall disproportionately upon any one segment.

3. That strong case management requirements are included in order to ensure that financial resources are expended in the most effective and efficient manner.

Thank you.

Chairman PEPPER. Well, we thank you, Dr. Northway. That was a magnificent statement.

Our next witness is Dr. Josephine Gittler of the National Maternal and Child Health Center at the University of Iowa, Iowa City.

STATEMENT OF JOSEPHINE GITTLER, J.D.

Dr. GITTLER. Thank you, Mr. Chairman. I do want to express my great appreciation for the opportunity to appear before this very important hearing today on behalf of the National Maternal and Child Health Resource Center. Because of time limitations, I would ask that my written statement be submitted for the record and I will confine my remarks to very brief observations.

I think you heard this morning from the panel of parents just how devastating catastrophic child health problems can be for the child and the family.

And this is something that we at the Resource Center have become very conscious of. Sitting in the audience today is Mrs. Julie Beckett who is the Associate Director of the Resource Center. She is the mother of Katy Beckett, the little girl whose plight resulted in a change in Medicaid under which a child that was institutionalized could receive Medicaid benefits, but when she went home she could not receive Medicaid benefits because of her family's income being too high to qualify for benefits when she was at home.

Julie receives innumerable calls from parents all over the country on a weekly basis, who do not have private insurance, have private insurance but it's inadequate and who are having problems in working their way through Federal and State bureaucracies to obtain any relief from public programs.

In fashioning some kind of Federal response to the problem of children with catastrophic health problems, I know you all are aware of the difficulties that come about just because there's no agreed definition of what constitutes catastrophic child health problems.

Traditionally, these kinds of problems have been defined in terms of total annual health care expenditures above a certain amount. I'd like to suggest to you that another way of defining them is to look at children that have certain kinds of diagnoses or have certain kinds of functional limitations, and there is some precedent in formulating legislation to take the latter approach in the security income program that covers blind and disabled children.

I think the previous panelists have indicated that the prevalence of catastrophic child health problems is not that large. It really does appear that children represent a relatively small proportion of the total catastrophic expenses. When you look at the prevalence of common handicapping conditions in chronic illnesses what you find is that they are fairly rare in the general child population. Likewise when you look at the proportion of children that have some limitation on normal activity, such as play or school, you find that they constitute a relatively small proportion of the child population.

Now, I mention this because I think it's significant in terms of your responsibilities in fashioning a Federal response to this problem, because it may really, it really does seem that taking care of these children with catastrophic health problems need not cost as much as sometimes people think it may. I mean, they are a relatively small proportion of the population, albeit they are high cost.

We have heard a lot of testimony about the magnitude of expenditures for children with catastrophic health problems, and I will not repeat the information in my written testimony on that matter but I will simply refer you to my written testimony.

You have also heard extensive testimony about the lack of insured coverage of children with catastrophic health problems or the inadequate insurance coverage of children with catastrophic health problems. I would really like to submit to you that the problem of underinsurance is equal to the problem of uninsurance. What we have seen both in the statistical data that we have collected and what we have seen on the basis of the families that we have come in contact with is that there are a significant number of families with children with serious health problems that do have some sort of health insurance, either private or public, but it is simply inadequate to cover the expenses that they incur in connection with treatment, rehabilitation of their child. And so I think any solution that you all formulate to the problem of children with catastrophic health problems really must take into account the problem of uninsurance as well as the problem of underinsurance.

Turning to policy implications and recommendations, two of the previous panelists have referred to the State Crippled Children's Program. Actually they are now called Programs for Children with Special Health Care Needs. In the Federal legislation, Title 5, Maternal and Child Health Services Block Grant.

I would like to suggest that in formulating any Federal response to this problem of children with catastrophic health illnesses and conditions that a strong role be given to the State programs for children with special health care needs. These programs are already receiving Federal assistance under the Title 5 Material and Child Health Services Block Grant. Many of them are heavily State funded.

Mr. Chairman, in your own State of Florida, for example, the State Crippled Children's Program, over 90 percent of its budget comes from State funds. Under 10 percent of its budget comes from Federal funds under the Title 5 Maternal and Child Health Block Grant.

These programs have been trying to fill the gap caused by inadequate private health insurance, and lack of adequate public health insurance programs. But their budgets oftentimes have just not been sufficient for them to do what they should be doing, even though they do fund care for a substantial number of children with catastrophic health problems.

They also are programs that have a lot of expertise in setting standards for care for these particular kinds of children that we are talking about today so as to assure adequate quality of services and for doing planning of care and case management for these children so that the multiple servcies that these children need from multiple sources are adequately coordinated.

So again, I would suggest that any Federal solution take into account the current role of the Title 5 State programs for children with special health care needs.

I also would ask that you direct your attention in formulating a Federal solution to the State Medicaid programs and you've already heard alluded to the fact that these programs do not cover many poor children at the present time who have catastrophic health problems and even when they do provide coverage, they do not give some of these children appropriate access to needed health services because of limitations they place on mandated services and their failure to cover optional services.

They also are not doing in many instances the job they should be doing in terms of quality assurance and in terms of care planning and coordination of services.

In short, I think there are two existing Federal programs that do relate to children with catastrophic health problems who are deserving of your attention in terms of looking at ways that they can be improved to do what they should be doing, but all too frequently aren't doing.

Thank you.

[The prepared statement of Dr. Gittler follows:]

PREPARED STATEMENT OF JOSEPHINE GITTLER, J.D., CODIRECTOR, NATIONAL MATERNAL AND CHILD HEALTH RESOURCE CENTER, UNIVERSITY OF IOWA, IOWA CITY, IOWA

My name is Josephine Gittler and I am testifying here today on behalf of the National Maternal and Child Health Resource Center. The National Maternal and Child Health Resource Center collects, analyzes, and disseminates information and data about public health care programs serving mothers and children; conducts research and prepares reports about maternal and child health services; provides consultation and technical assistance to programs serving children with special health care needs; and prepares education and training materials and conducts training and education programs with respect to children with special health care needs.

The Resource Center is currently administering a project entitled, "Future Directions of Services for Children with Special Health Care Needs," sponsored by the Division of Maternal and Child Health, BHCDA, HRSA, Public Health Service, U. S. Department of Health and Human Services. In connection with the project, the Resource Center is engaged in a major national study of financing of care for children with special health care needs (children with disabilities, handicaps and chronic illnesses). As a result of this project, we have collected data and information relevant to the subject of this hearing--namely, the catastrophic health insurance needs of children.

IMPACT OF CATASTROPHIC CHILD HEALTH PROBLEMS

The high cost of care for children with serious health problems can have a devastating impact upon children and their families. The following cases are illustrative:

Rose and Louise R.1/

On April 30, 1981 Rose and Louise R. were born 2 1/2 months prematurely. Because of prematurity, both babies had serious health problems. Rose was transferred to the neonatal intensive care unit of a Los Angeles hospital. After 2-1/2 months of hospitalization, she died. Louise remained in the neonatal intensive care unit of the hospital for 1-1/2 months. While there, she had a brain (intraventricular) hemorrhage requiring surgery for placement of a shunt to drain excess fluid and relieve the pressure, and about 3 months after her initial discharge from the hospital, she was rehospitalized for an emergency shunt revision. In the last several years, she has had numerous hospitalizations for various problems.

Louise is now 6 years of age and is cared for at home. Because of breathing difficulties, she has a tracheostomy and is oxygen dependent requiring the provision of air with an increased concentration of oxygen on a 24-hour basis. She also has a gastronomy tube to assist in her feeding. She is blind and retarded.

The family of Louise and Rose consists of a father, mother and 5 siblings, of which one is still at home. The family is a middle-income family with the father employed as a truck driver and the mother employed as clerk in a law firm.

When Louise and Rose were born, they had no private insurance coverage. Their father had applied for private insurance coverage for himself and his dependents offered by his employer, but he coverage had not yet become effective. The family received some assistance for payment of hospital bills from the state Crippled Children's Services, but this assistance did not result in total payment. Because of unpaid hospital bills for which the father was legally liable, the father's wages were garnished, and the father eventually filed a federal bankruptcy petition which was granted.

Once the father's private insurance policy became effective, Louise had coverage for both hospital and home care. The annual cost of her care is currently about $200,000. Her care at home requires 24-hour nursing care, visits by or to a physical therapist, a respiratory therapist and a physician. Her home care also requires special equipment, a special formula, medications and a variety of disposables. In addition, she is periodically hospitalized.

The father's employer recently switched insurance carriers, and as of August 1 of this year, Louise will be covered by a new policy. This policy has a lifetime maximum benefit of $250,000 and does not pay for in-home nursing care. Since the annual costs of Louise's care are approximately $200,000, the maximum benefit would be exhausted within 1-2 years, and since there is not coverage for the in-home nursing care, amounting to about $10,500 a month, which is needed if she is to remain at home, she would have to be institutionalized.

For six months, Louise's parents sought help from a number of public programs without success. For example, Louise's parents were told that she is not financially eligible for the regular state Title XIX Medicaid program because her parents' financial resources are too high. They were also told that she could qualify for Medicaid benefits if she was institutionalized because then their income and assets would not be counted in determining her

financial eligibility. While the state has a Medicaid "waiver" program that will provide payment for care for children transferred from an institutional setting to a home/community setting who would not ordinarily be financially eligible for Medicaid benefits at home, they were told that she does not qualify for this program. They have recently been informed that the state has applied for a Medicaid "waiver" that will allow Medicaid coverage of her home care costs. They, however, understandably remained concerned about whether they will receive adequate coverage of her home care costs.

Anne M.[1]

Anne M. is almost 6 years of age. She has a possible degenerative disease of the nervous system that has resulted in a low level of functioning.

In July of 1981, when Anne was 3 months old, she was hospitalized for a seizure. During 1981-1983 she was hospitalized on numerous occasions for treatment of seizures, recurrent pneumonia, and a variety of diagnostic procedures including brain and liver biopsies. Since 1984, her hospitalizations have substantially decreased because there has not been recurrence of her pneumonia.

Anne was cared for at home except during periods of hospitalization from 1981 until August 1986, at which time she was placed in a skilled nursing home. At the time of placement, the annual cost of her care for both hospital and home care was approximately $114,000.

Anne's family consists of her father, mother and one sibling. They are a middle-income family with both parents being self-employed in the operation of a company that markets products to retailers. From 1981 to August 1986, Anne had private health insurance coverage under her fathers' health insurance policy. The premium for this policy was subject to annual review and increased dramatically due to the cost of Anne's care. In 1981, prior to Anne's birth, the premium was $100 a month; in 1985, the premium was $1300 a month, and in 1986, Anne's father was notified that the 1986 premium would increase to $1900 a month, amounting to $22,800 a year.

Unable to afford the increased cost of the premiums for private health insurance, Anne's parents sought help from various public programs. They were informed that Anne's would not be financially eligible for the state Medicaid program because of her parents' income and assets unless she was institutionalized, in which case her parents' income would not be attributed to her for purposes of determining program financial eligibility. Her parents, however, wanted to continue to care for her at home, and when they learned that the state Medicaid program had a special Medicaid "waiver" program allowing payment for home care for children at risk of institutionalization who would not otherwise be eligible for Medicaid benefits, they applied for Anne's admission to the program. They were notified that the waiver program served only 50 people and Anne was 246th on a master waiting list.

Since Anne's parents could not obtain financial assistance to pay for her home care, they reluctantly placed her in a skilled nursing facility. This facility is an over three hour drive from Anne's home, which makes it difficult for her parents to visit and monitor her care.

DEFINING CATASTROPHIC CHILD HEALTH PROBLEMS

Catastrophic child health problems are often defined in terms of the total annual health care expenditures greater than a certain amount, in terms of total out-of-pocket expenditures in excess of a fixed amount, or in terms of out-of-pocket expenditures exceeding a proportion of family income. These problems, however, may also be defined in terms of specific diagnostic conditions or in terms of functional limitations that make children at risk for large health care expenditures.

PREVALENCE OF CATASTROPHIC CHILD HEALTH PROBLEMS

One approach in determining the extent of catastrophic childhood health problems is to identify the proportion of the child population who have large health care expenditures. A 1980 report of the American Academy of Pediatrics concluded that "children represent a small proportion of the total catastrophic expense bill."[2] Another approach in determining the extent of catastrophic childhood health problems is to estimate the prevalence of handicapping conditions and chronic illnesses among children, inasmuch as children with such conditions and illnesses are likely to have catastrophic health care expenditures. Prevalence can be estimated by reference to specific conditions and illnesses among children or by reference to activity limitations among children. National prevalence estimates have been developed for 22 of the most common chronic childhood disorders based upon an exhaustive review of the literature, and these estimates indicate that the prevalence of common chronic childhood disorders is quite low.[3] An analysis of the most recently available data from the National Health Interview Survey indicates that a relatively small proportion of the child population under 18 years of age has moderate to severe limitations as to usual activities (e.g., play or school).[4]

It should be noted that the aforementioned estimates relating to the extent of catastrophic child health problems are derived from data sets which are not current. Since AIDS may have the effect of increasing the number of children with catastrophic health problems, these estimates may change as

data about the prevalence of AIDS among newborns and children becomes available.

MAGNITUDE OF EXPENDITURES FOR CATASTROPHIC CHILD HEALTH PROBLEMS

Existing information about health care costs incurred by a group of children, known as technology dependent children, demonstrates just how great the costs of care may be for children with catastrophic health problems. While the technology dependent child population may be defined in a variety of ways, it generally includes children who use medical devices or equipment to compensate for loss of a bodily function and who require regular nursing care, with the most publicized of these children being those who are dependent upon a ventilator for assistance in breathing.

-- Technology dependent children are generally initially hospitalized for an extended period of time, and it is not unusual for the cost of the initial hospitalization to exceed a hundred thousand dollars.
  - o Preliminary analysis of data regarding children enrolled in the Pennsylvania Ventilator Assisted Children/Home Care Program indicates that the average cost of hospital care for these children after their condition has stabilized in the month prior to discharge is $34,800.
  - o Preliminary analysis of data regarding children enrolled in the Home Care Program conducted by the Maryland Coordinating Center for Home and Community Care indicates that the average cost of hospital care for these children after their condition has stabilized in the month prior to discharge was $24,800.
-- While home care of these children is less expensive than hospital care, the cost of home care is nevertheless significant.
  - o Preliminary analysis of data regarding children enrolled in the Home Care Program conducted by the Maryland Coordinating Center for Home and Community Care indicates that the average start-up cost of home care was $9,000 and that the average monthly cost of home care after the first month at home was $9,000.
  - o Preliminary analysis of data regarding children enrolled in the Home Care Program of the Illinois Division of Services for Crippled Children indicates that the average start-up cost of home care was $8,000 and the average monthly cost of home care after the first month was $5,500.2/
-- Even after these children are discharged from the hospital to their homes, they often are rehospitalized for various problems.
  - o Preliminary analysis of data regarding children in the Illinois Home Care Program indicates that the average cost of rehospitalization was $8,500.2/

INSURANCE COVERAGE OF CHILDREN WITH CATASTROPHIC HEALTH PROBLEMS

Available data indicate that children 0-17 years of age constitute the largest segment of the uninsured population under the age of 65.1/ However, precise estimates of the uninsured child population vary, depending upon the source of data, the date when the data were collected, and the age of the children involved. Taken as a whole, available data suggest that a significant proportion of the child population under 18 years of age lack health insurance coverage, private or public (e.g., Medicaid), all or part of the year.1/ It should be noted that up-to-date information about the current proportion of the child population that is uninsured is not available, but that there is widespread agreement that there has been a growth in underinsurance among children in recent years.

Underinsurance is as much a problem as uninsurance for children with catastrophic health problems. Even when children with catastrophic health care problems have private third-party coverage, limitations often restrict the utility of private insurance benefits for them. Thus, private health insurance policies often have maximum lifetime benefits which in the case of a child with a catastrophic health problem may be exhausted while the child is still in high-cost health services for an extended period of time; private health insurance policies also often require co-payments, which in the case of a child with a catastrophic health problem may be quite large; in addition, health insurance policies not infrequently exclude from coverage or place limits upon certain types of care and services that children with catastrophic problems may well need.1/

Just as private health insurance coverage does not guarantee that the costs of needed health care will be covered, public insurance coverage does not guarantee that the costs of needed health care will be covered. Families of children with catastrophic health problems often turn to the state Title XIX Medicaid programs, but even if a child with catastrophic health care problems is Medicaid-eligible, the extent to which the program assists such a child depends on the extent to which the program provides reimbursement for services the child needs. A number of states place limits on mandated services and exclude from coverage various optional services.2/

POLICY IMPLICATIONS AND RECOMMENDATIONS

The foregoing dictates the conclusion that the present system of private and public health insurance is not protecting a significant number of

families from the financial risks and burdens of catastrophic health expenditures. There are, however, a variety of federal initiatives that could reduce the uninsurance and underinsurance among children who have health care problems resulting in expenditures of a catastrophic nature.

One approach would be the enactment of federal legislation establishing a federal catastrophic health insurance program covering children. As it has been pointed out, catastrophic child health expenditures make up a relatively small proportion of total catastrophic expenditures so that it appears that the cost of federally subsidizing catastrophic health insurance for children may be relatively low. A program that subsidizes catastrophic health expenditures for children could be administered at the state level through State Programs for Children with Special Health Care Needs (CSHC Programs), formerly called the State Crippled Children's Services Programs. The CSHC programs receive federal assistance under the Title V Maternal and Child Health Services Block Grant, and many of the CSHC programs are heavily state funded. One advantage of this approach is that a large number of these programs are already third-party payors for services for children with serious health problems requiring high-cost care. Another advantage of this approach is that CSHC program personnel have considerable expertise in formulating standards of care for and monitoring the quality of care provided children with serious health problems, and equally important, they have expertise in care planning and provision of case management services to this population.

Another approach is to expand Medicaid program eligibility and give states the option of allowing uninsured or underinsured families of children with catastrophic health problems to purchase Medicaid benefits with an income-adjusted premium. Expansion of Medicaid eligibility to poor and near-poor children is highly desirable. Whether, however, a Medicaid "buy-in" is an optimal or even realistic mechanism for dealing with uninsured and underinsured children with catastrophic health problems is open to question. The fact that many states are not fully utilizing existing Medicaid options for provision of coverage for such children raises doubts about the likelihood that states will take advantage of a Medicaid "buy-in" option. Moreover, in many states where such children are Medicaid eligible, they do not have access to needed services because of limitations on mandatory services and failure to cover optional services, and they also may not have access to needed services because of resistance of health care providers to participate in state Medicaid programs. Moreover, state Medicaid programs frequently do not have adequate mechanisms to assure quality of care which are of particular importance to such children, and they frequently lack the capacity for the care planning and the provision of case management services which are of particular importance to these children.

A somewhat different approach to helping families with catastrophic health problems would be the enactment of federal legislation mandating or offering incentives for the creation of state high-risk pools which are generally aimed at enabling individuals who are considered high-risk and hence uninsurable to obtain comprehensive health insurance at reasonable prices. A high-risk pool spreads the risk of loss in covering a population at risk of incurring high-cost health care across all participating insurers, thereby reducing each insurer's risk. The creation of such pools could be of particular benefit to uninsurable children with catastrophic health care problems and could also be designed so as to benefit underinsured children with catastrophic health care problems. Although the high-risk pools that have been established in several states are not without their deficiencies, there appear to be ways to correct these deficiencies.

A related but nonetheless distinct approach utilizing the private sector would be the enactment of federal legislation mandating or offering incentives to employers for the extension of minimum health care benefits to their employees and the dependents of their employees. Depending upon the benefits involved, such legislation could be of assistance to underinsured families of children with catastrophic health problems.

FOOTNOTES AND REFERENCES

1. The cases described are actual cases. However, the names of the children have been changed so as to protect the privacy of the children and their families. The information pertaining to these cases was furnished by the children's parents.

2. American Academy of Pediatrics, Child Health Financing Report, Vol. II, No. 3, Spring 1986. The report states that provisional analysis of the 1980 National Medical Care Utilization and Expenditure Survey indicated that less than 1% of non-institutionalized children under 19 incurred total medical expenses greater than $5,000 in 1980; only 0.6% of all noninstitutionalized children under 19 incurred out-of-pocket expenses greater than 10% of their family income; and less than one-quarter of 1% had out-of-pocket expenses

greater than 30% of the family income.

3. S. Gortmaker, "Chronic Childhood Disorders: Prevalence and Population, Now and in the Future," a paper prepared for the National Maternal and Child Health Resource Center (1985). According to Gortmaker, the following common chronic childhood disorders have an estimated prevalence of less than 1 per 1,000: sickle cell disease including sickle cell anemia (.46), neural tube defect including spina bifida and encephalocele (.45), autism (.44), cystic fibrosis (.20), hemophilia (.15), acute lymphocytic leukemia (.11), phenylketonuria (.10), chronic renal failure (.08), muscular dystrophy (.06), traumatic brain injury (.05). The following common disorders have an estimated prevalence of more than 1 per 1,000: moderate to severe asthma (38), visual impairment (30), mental retardation (25), hearing impairment (10), congenital heart disease (7), seizure disorder (3.5), cerebral palsy (2.5), arthritis (2.2), paralysis (2.1), diabetes mellitus (1.8), cleft lip/palate (1.5), Downs syndrome (1.1). Ibid.

4. The National Health Interview Survey indicates that 0.5% of children under 18 years of age are unable to engage in major usual activities; 3.2% are limited in the amount or kind of usual activities. National Center for Health Statistics: Current Estimates from the National Health Interview Survey: United States 1985. Vital and Health Statistics, Series 10, No. 160 (Sept. 1986).

5. National Maternal and Child Health Resource Center, "Financing Care for Technology Dependent Children," (draft) (1987).

6. M. Sulvetta and K. Swartz, The Uninsured and Uncompensated Care: A Chartbook, National Health Policy Forum (June 1986).

7. Based upon national data sets from 1977 to 1984, the proportion of the child population that is uninsured has been variously estimated as 17.5% (children under 18 years of age), 21.7% (children under 18 years of age), 20.9% (children and youth under 22 years of age), 18.6% (children under 17 years of age), and 15.5% (children under 16 years of age). American Academy of Pediatrics, supra n.2; M. Sulvetta and K. Swartz, supra n.6.

8. A recent survey of 55 employer-based private health insurance plans revealed that 67.3% had some type of lifetime maximum benefit ranging from $100,000 to $1,000,000, and that 36% excluded home care from coverage. M. Fox and M. Veshpe, "Private Health Insurance Coverage of Chronically Ill Children," a report prepared for the National Maternal and Child Health Resource Center (March, 1986).

A recent survey of private coverage of technology dependent children enrolled in the Pennsylvania Ventilator-Assisted Children/Home program who had private insurance coverage revealed that 44% of the insurance plans involved had some type of overall ceiling on expenditures, that 41% excluded from coverage or limited coverage of medical equipment and 39% excluded from coverage or limited coverage of in-home nursing care. National Maternal and Child Health Resource Center, supra, n.5.

9. A recent survey of 42 state Medicaid programs revealed that in a substantial number of states, services needed by high-cost children with handicapping conditions or chronic illnesses would not be covered. S. Davidson, "Medicaid and Children with Special Health Care Needs," a paper prepared for the National Maternal and Child Health Resource Center (January 1987).

Chairman MILLER. Thank you. Dr. Perrin, you have a time problem?

Dr. PERRIN. I've just got patients scheduled this afternoon.

Chairman MILLER. Let me just, if I can, ask you one question. And I hope to get together with you later on this.

But is perhaps the term catastrophic here a misnomer? I think both you and Dr. Northway pointed out that in the past we've thought about that as a sort of an episodic event—boom, it happened to somebody and nobody had the resources to deal with that.

But if you listen to these families, we are really talking about a lifetime maintenance operation here in services, and that's where it seems to me a great number of the gaps exist. How do you get attendant care, how do you get home nursing care, how do you get mobilization, how do you get transportation. How do you provide all of these resources so that young people, whom 15 or 10 or 25 years ago we didn't think would live the semblance of a normal life, today are going to live a very normal life.

A paraplegic today has very few limitations placed upon them in terms of their opportunities in society, except that he or she can't get around because there's not a body of services available to young children at the table here.

There is no indication that they won't go on to school, that they won't live some notions of a reasonable life. Randy is the same way.

And it seems to me that that's not quite as romantic or as exciting for policy makers, but as I've listened to these families over the years, it's the most mundane need that they have on a daily basis, that would drive most of us right up the wall and certainly drives them up the wall.

And yet there seem to be all of these stumbling blocks. I guess my question is, why would a hospital or insurance company make a decision not to provide these services? I mean, what is the rationale that leads you to do what apparently is financially against your own best interest, for a number of these organizations?

Yet we see it repeated over and over and over again both in the private and the public sector.

Do you have 30 seconds to answer that question, Dr. Perrin?

Dr. PERRIN. I think you're absolutely right, Mr. Miller, that it is not an issue of catastrophe of an acute, short event. Some teenagers have accidents in which there may be an acute catastrophe. But still, it's a lot of long-term care afterwards even for this group.

It may be expensive for the first few months. It still is expensive thereafter. And I wouldn't lose sight of that. We are talking about long term care for children.

I think the reason that insurers have been hesitant to get into this, and this is a tremendous service that you and your group can provide, is because they have not understood the scope of the problem. They have had concerns about whether there is an opportunity for this to be such a large problem they can't pay for it. We can define that number and I think we can see how it can be paid for.

Chairman MILLER. If I'm an insurer and I have a young person who is going to need a lifetime of services, I guess it's much easier for me to think we'll get the first $100,000 and we get rid of these people. This family, you know, they're no longer our obligation. We

75-154 O - 87 -- 4

don't have to deal with this on a monthly basis, change of location, change of employment and all this. Let's just spend the $100,000 and get them out of here. Is that going on?

Dr. PERRIN. Yes. The most cost efficient care for these children would be a form of genocide. The cheapest way is to encourage these children not to survive. That's not an acceptable public policy.

Chairman MILLER. Thank you very much for your coming down here and for the benefit of your testimony. And thank your patients.

Chairman PEPPER. Are you leaving, Doctor?

Chairman MILLER. Yes, he has to go.

Chairman PEPPER. Very well. We want to thank you all very much for being here. I'd just like to ask you one question.

Is there any likelihood that with the limited coverage that private insurance will almost of necessity have, is there any likelihood of this problem adequately being met without the overall direction and the overall participation of the Government of the United States?

Dr. PERRIN. I think the Government of the United States can provide a series of important incentives for the private health insurance market to be much more responsive to the needs of the families that we've heard today. We must go beyond that, though. We've really got to deal with a series of issues that are not so simple. How do we get children access to health services or hospital care. We need to go beyond that and I think that's a very important role for the Federal Government, to help us with that second task.

Chairman PEPPER. What would be your statement, Dr. Northway?

Dr. NORTHWAY. Well, I would basically agree with that. I think that one of the things that happens when we select out certain groups, those groups end up being the most costly group to care for and their costs usually end up being paid by the government.

I think if there was some kind of situation where—and no one likes mandates and I'm not sure you can ever get mandates through—all business carried some kind of health insurance, then you can spread all of this risk out amongst the whole population and that reduces the risk for any one individual.

When you begin to select out people, then I think what happens is that those people fall into the government's baliwick and in order to get into the baliwick you have to basically sell your house and do away with all your own resources before you get cared for. I don't think that's the most appropriate way to do it. If we could certainly encourage everybody, all small businesses, now, granted there are some costs there and maybe there could be some cost shifting or somehow, but if we could mandate insurance coverage, I think in large part we would begin to do away with the financial burden being placed on just a few people. Like in California, for instance, if we took all of those——

Chairman PEPPER. Can anybody other than the government distribute the risk over the whole population?

Dr. NORTHWAY. Although I'm not an insurance person, I would think that if everyone who worked had an adequate basic family

health insurance policy that the risk then would be spread across the country. I think that could be handled by the private sector rather than from the government and it would be just those people who don't work or who are poor and——

Chairman PEPPER. Under that sort of a system, would it not be comparable to the situation where Chrysler Motor Company says that it adds $600 to the cost of each car to provide medical care for its employees? In other words, isn't the public paying the bill anyway?

Dr. NORTHWAY. Yes, I suppose they are. The public is going to pay for it one way or the other. I guess the real question comes to whether we should try to do it first in the private sector and then those people who absolutely fall out, there would be a net that the State and Federal Governments would take care of.

Dr. GITTLER. I do think that there are two different kinds of roles for the Federal Government. One is to subsidize care directly or indirectly. The other as has been mentioned is to provide some incentive to the private sector to provide more and better care and I personally believe that the creation of State high risk pools is a very encouraging development.

Now, I think Congress should take a look at what mandating or providing incentives for the creation of State high risk pools might do for this population that we are concerned about.

There have been some serious deficiencies in the State high risk pools that have been created but I think there are ways of correcting those deficiencies.

Congress can also as is now being considered mandate certain benefits be provided by employee based health insurance plans.

Now, there are lots of questions about that approach in terms of its impact on small businesses and in terms of some of the prohibitions of ERISA that would have to be waived vis-a-vis self insurers. But I would suggest that maybe there's not one approach that is the total answer but there can be a combination of approaches that reinforce each other with no one approach being mutually exclusive of other approaches.

Can I just make one comment, Congressman Miller?

One of the reasons I said that I thought it was important to think about defining catastrophic health problems not just in terms of total expenditures on an annual basis, but in terms of some kind of functional limitations, is precisely the point that you made a few minutes ago.

There are lots of families that have children with serious health problems that occur over a long period of time that require expenditures over a long period of time for a multiplicity of services, not just health, but social services, educational services and a variety of support services.

Their total expenditures in any given period, part of a year or a year, may not be that great, but when you know that they're going to have to be paying for that child over years then you know the problems of the child become catastrophic in nature even though those children may not fit traditional definitions of having catastrophic health expenditures.

That's why I think we need to focus on the nature of the health problem and the degree to which the child is functionally limited in designing some sort of solution.

Chairman PEPPER. I regret that I'm going to have to go. I want to join Mr. Miller in extending the warmest thanks to all of you and to the panel that's coming up next for the wonderful contribution you've made here today.

Thank you.

Thank you, Mr. Chairman, very much.

Chairman MILLER. Thank you, Mr. Chairman, very much for joining us in these hearings.

What bothers me a little bit is that in a number of the instances we heard about today, and it's true at the other end of the age scale—I remember that the President, when I worked in the State Legislature, was fighting very hard for relatives' responsibility at that time and it's a concept that we all generally endorse in terms of the ability of the family to contribute something to the care of either our elderly or our children.

But it doesn't seem to me that the system focuses on the individual who needs the services. We bring in all of these ancillary facts of whether the family is working, whether they have a home, and we spend more time sitting down with Brazil to figure out how to fashion a plan for repayment than we do with the family and say what is it that you can or cannot do?

Instead it seems we let you go down for two and a half times, and then maybe we pull you back above the surface and start to put in place something that is marginal at best.

There is nothing unusual that you hear from one of these families that is involved in this with young children, which is where I have spent most of my time, in terms of the committee.

These stories of the stress and the complications that families have can be told a million times in this country. But we seem to diminish the opportunity of the families to participate in the care.

The young man said that his mother was serving as his attendant. Now, his mother gave up her job to serve as an attendant. But we wouldn't pay his mother the minimum wage to keep the young man out of the hospital to replace some of the family income due to an accident that was clearly unforeseen and nobody's fault. But we're going to let that family become impoverished, we're going to let that family come under additional economic stress. And at the same time they can continue to wonder for the rest of their life certainly, in this young man's desire to go out to college or to have an independent life, whether or not care is going to be there. Just live with that on a daily basis.

It seems to me that that is just the opposite of what we say as policy makers we want for the American family. The interesting thing is that it doesn't seem to be terribly much more expensive than this slipshod system that we have today. But we don't have a system that focuses on the person in need of the services and what are those needs, whether it's long term or even immediate, and the hospitals in a sense have to do it because they have little or no alternative. You are having a delivery, you have a low birthweight baby, you have the need and you immediately apply the services in

that short time frame, or the same thing in terms of a stroke or cancer.

But once you get out of that episode, we—everybody—kind of drifts away from you at that point and kind of abandons you.

Mr. Vento?

Mr. VENTO. Thank you, Mr. Chairman.

I don't think I have ever been as quiet for as long a time—but I didn't hear anything I disagreed with. I think the witnesses have been very good and your comments are very apropos.

I recall dealing with a related issue which they called a Foster Care Income Amendment that we had added. Charlie Rangel and I worked together on it some years ago with our Senate counterparts and the incredible thing is the IRS was going to charge income tax on a per diem payment for foster parents that were dealing with individuals with severe disabilities because they couldn't demonstrate the differing costs for cleaning up the ice cream on the floor and so forth when you're dealing with children with disabilities.

So the fact of the matter is that they still, in terms of Tax Code, are having a hard time. Foster parents that are willing to deal with children that have various types of disabilities and are trying to take care of them in a home setting are being treated unfairly.

I mean, it's absolutely incredible. So I think the fact is that clearly there is a need. I mean, if anyone doubts there is a need, just look at the title of the program—Crippled Children's Program. I mean, that's 1940's jargon or something. We haven't done a whole heck of a lot in recent years in terms of putting together this policy. It appears to me it probably started out with a lot of good intentions and I in no way criticize those that use that terminology in the 1940's or the early 50's, it was probably appropriate.

But fortunately today we do use different terms. But there is a need to coordinate. And you know I think the answer to sort of begging is the one that you implied in your comments, George, and I'm sure that most of the professionals that deal in this area and study it know what the national government and the insurance companies are depending upon. They are depending upon families who act like families.

They expect families to take on the responsibilities and not receive any support. And of course as the technology and the lifesaving capabilities of the medical science today prove more successful of course, the old medical model doesn't work.

I was just recently in my district and visited with a person that was the cochairman or founder of Health Care Advocates. She's a 30-year-old woman that has ALS disease and the only thing she can do is move her eyebrow. She communicates through a computer and goes around to hospitals trying to tell people they don't have to stay in hospitals, they can go into private living situations.

Of course, as I said, the government and the programs that we have as well as the insurance programs depend upon families to quit their jobs, to take over, to do these tasks. As a consequence, of course, then the companies and the Government don't bear the risk, they don't pay the dollars.

I don't know what the total cost of the program that dealt with this would be but I do know that we should begin to modify our

policies to facilitate this type of care, because of the values we have as a society and because it just tends to make a lot of sense.

It's not going to be easy to do, as is indicated by my fight with the IRS. And finally we had to change the law. We couldn't get a ruling on that.

We had to finally change the law so it would permit the parents or the foster parents, to not pay the income tax on the extra per diem payment for a handicapped or a disabled child.

I mean it's incredible, but that was the case. So I really don't have any questions of this panel, Mr. Chairman; I think it's a good hearing and I'm sure that out of this type of understanding we will find a policy path that will begin to make some common sense in terms of home health care for children and for others.

Thank you, Mr. Chairman.

Chairman MILLER. Thank you.

Dr. Northway, I just have one remaining question.

If I read your testimony correctly, you talked about the fact that in California we have the situation where ½ of 1 percent of the 500,000 children admitted to the hospitals were accounting for $280 million of the expenditures. If I try to marry that with Dr. Perrin's testimony from the American Academy of Pediatrics, and his numbers around newborns hospitalized 16 days or longer, obviously, it really starts to jump out at you that we're still a long way away in terms of having a quarter of a million low birthweight babies. All through this hearing, with your testimony and Dr. Perrin's, they start to show up in that grouping.

Is that correct? I mean is that the same as in California, that's the bulk of the cost?

Dr. NORTHWAY. I believe so. I think that if you're starting to spend limited monies, you need to put it in the right place. Teenage pregnancies would be one place to begin. Teenage pregnancies are usually high risk pregnancies. If you can get these young women into the health care system early in their pregnancy, you may be able to reduce the chance of producing small premature baby which will have a long hospital stay and develop some of the problems that you witnessed this morning.

I believe there really are some things which we can do to reduce the number of premature babies and this is important as a small number of children who are premature really do generate huge costs because of all the technology and personnel involved in their care.

Chairman MILLER. Now, at Valley Children's, where you have such a high caseload of Medicaid eligible people, is that the same trend you're seeing there in terms of adolescent pregnancies and pregnancies that——

Dr. NORTHWAY. I believe so. I can't give you the specific numbers or the percentage of our babies that come from high risk pregnant mothers, but—and many of those are teenagers—it's quite high. We work very closely with the county hospital there and they have, they are developing a teenage pregnancy program and so we're hoping that we're going to begin to get to some of these young women to get them to get good care so that in fact we can, and maybe this is not the right thing for a hospital administrator

to say, so that we can empty out, begin to empty out some of our newborn intensive care.

Chairman MILLER. So that would be where a disproportionate share of your cost would show up also?

Dr. NORTHWAY. Right.

Chairman MILLER. In terms of pregnancies that are abnormal?

Dr. NORTHWAY. Approximately 35 or 40 percent of our inpatient days are in the NICU.

Chairman MILLER. OK.

Dr. NORTHWAY. So it's a big problem. For many of these newborns, the outcome is good, although expensive, because they may be hospitalized for 2 or 3 months. But then unfortunately, there's a whole host of them that go on and develop either chronic lung disease or they have some neurological impairment or other problems.

If we can begin to get to those young mothers into the system early, that would obviously be a step in the right direction.

Another area to look at is trauma. Injuries take more lives in pediatrics probably than anything else. Once these injured children get into a health care facility, particularly with the very good paramedic programs and all that kind of thing we have, these children generate very large bills. You saw a young man sitting here who benefited from good modern health care. Probably 10 years ago he might have been dead, but today he sits here a young man who has a future ahead of him even though he's impaired, but unfortunately has no way to pay for it and to get into society.

So those are two areas that we need to look at.

If by spreading the premium cost across the whole population we may not devastate a few families by an illness which they had no way to plan for.

Chairman MILLER. Well, thank you. Thank you.

Next, the committee will hear from Sara Rosenbaum, the Director of Child Health for the Children's Defense Fund, and Dr. Constance Battle who is the Medical Director and Chief Executive Officer for the Hospital for Sick Children in Washington, DC.

Welcome to the committee.

PANEL THREE—THE RESPONSE TO THE CATASTROPHIC HEALTH CARE NEEDS OF CHILDREN: CONSISTING OF SARA ROSENBAUM, DIRECTOR, CHILD HEALTH, CHILDREN'S DEFENSE FUND, WASHINGTON, DC; CONSTANCE U. BATTLE, M.D., MEDICAL DIRECTOR AND CHIEF EXECUTIVE OFFICER, THE HOSPITAL FOR SICK CHILDREN, WASHINGTON, DC, ON BEHALF OF NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS; ROBERT SWEENEY, PRESIDENT, NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, ALEXANDRIA, VA; AND MICHAEL MORRIS, EXECUTIVE DIRECTOR, UNITED CEREBRAL PALSY ASSOCIATION, ON BEHALF OF CONSORTIUM FOR CITIZENS WITH DEVELOPMENT DISABILITIES, WASHINGTON, DC

STATEMENT OF SARA ROSENBAUM

Ms. ROSENBAUM. I have submitted a longer statement for the record and will just present a brief summary of my remarks.

I will address remedies. It is extremely important that in shaping remedies that we focus on the absolute catastrophies that we heard of this morning as well as what for lack of a better name I will call relative catastrophies, that is catastrophies that entail denial of access to primary and preventive services that might avert an absolute catastrophe but that are beyond the reach of many families.

Starting with absolute catastrophic needs, there are a number of steps that Congress could take that are really the topic of a long term debate.

Even though the issues relating to long-term care for the aged and catastrophic care for the aged are complex and politically difficult, they are easier than remedying children's plight, because there is a single large payer, namely Medicare. Once a political consensus about what need be done is reached by Congress, significant remedial actions can take place, which will aid all the elderly.

In the realm of under 65 health financing, however, we don't have one payer. We have multiple payers, public and private. As a result, forming a long term consensus about what health insurance ought to do for the under 65 population is extremely difficult.

Congress could amend both the Tax Code and the Federal Medicaid Statute as well as other public programs such as CHAMPUS, to build in catastrophic wraparound protections, just as it is now doing in the case of Medicare. Congress could also make benefit improvements, just as such improvements are now under consideration in the medicare debate. These improvements might include not only acute hospitalization benefits but also the range of home and community based care and case management services which have been discussed.

That is probably the best long term solution and is what Dr. Northway and other witnesses have discusssed. It would in fact spread the financial risk among all payers. It could be coupled with mandates for both systems to provide health insurance to people who have none at all.

The bill that Senator Kennedy is preparing to introduce in the case of private insurance would accomplish some of these goals, and Senator Chafee is preparing a bill that would broadly expand medicaid as a public insurer for people who do not have access to private care.

These are the appropriate long-term solutions. Insurance, both public and private, over the years has become a payer of normative health care costs.

The private insurance industry seeks people who have normative health care needs. That is what preexisting condition exclusions, lifetime and annual maximums, and diagnostic exclusion riders are all about.

Medicaid has dealt with this normative bias in a different way. States put annual limits on hospital coverage and physician services, for example.

Both types of payers are doing exactly the same thing.

We have a very basic philosophical decision to make. Do we want insurers—private or public—to act as normative payers or do we want them to finance higher cost services as well?

I tend to agree with the latter approach. But I don't think that this goal is achievable in the near future.

A number of things could be done this year however, to provide immediate relief. For example, the home and community based care option discussed by Josie Gittler, the option that brought Katie Beckett home, is an option that has been exercised by only 11 States.

Congress could decide to mandate that all States provide medicaid to children who could be moved out of an institution and cared for at home.

When the medicaid home and community care option program is available and combined with additional home and community based care services, it is a lifeline for these families.

Congress could also mandate that all States provide medicaid to children who are recipients of Supplemental Security Income. There are currently five States in the country that still categorically exclude disabled SSI children from their medicaid program because of a quirk in 1972 medicaid legislation that allows them to do this.

Congress could amend medicaid to make it possible to——

Chairman MILLER. What do we allow them to do?

Ms. ROSENBAUM. There are five States in the country that will not extend Medicaid coverage to children who receive SSI, because in January of 1972 prior to enactment of SSI there was no category of medicaid beneficiaries that were children who were disabled. Children were not part of the Federal disability program until 1974.

Congress, in enacting the SSI program in response to State fears about the added medicaid costs that would ensue, allowed states to take a snapshot of their programs as——

Chairman MILLER. We're good at that, huh? We take more snapshots than Kodak.

Ms. ROSENBAUM. That's right. That's right.

Chairman MILLER. None of them turn out to be accurate, but we take them.

Ms. ROSENBAUM. This snapshot literally shut the door to medicaid eligibility for disabled children in about five states.

I would say about once a month we get a call from one of the families in one of the States, who has discovered to its horror that even after it exhausted everything, it still can get no help under medicaid for a disabled child. But in a State such as Maryland, as you heard this morning, medicaid would provide relief.

That's an easy thing to take care of.

Congress might also implement a new provision in medicaid to allow medicaid agencies to buy employer provided insurance for people who are poor and working but cannot pay their dependents' insurance premiums themselves. This would give their children some base protection.

Finally, I urge that the committee look at the Title V program. Title V is the old Crippled Children's Services program. It is a good source of financing and technical aid to families with severely ill children. Until we deal with the issue how to finance children's absolute catastrophies through insurance, Congress could provide additional appropriations to State CCS programs to set up long-term

case managed care and financing programs for children who have literally exhausted everything else or who need case management assistance.

There are two serious problems with the existing Crippled Children's Program. First, many programs discriminate by diagnosis, thereby leaving out certain diagnoses such as cancer, leukemia, diabetes, and other conditions such as autism, other severe illnesses and ailments that result in catastrophic costs.

Second, most programs now use an upper-income limit test rather than some sort of threshold expenditure test to determine eligibility.

Both shortcomings should be remedied through a supplemental appropriation to Title V to fund a long-term resolution to the case management problem and a short term resolution to the financing problem.

With respect to relative catastrophies, the only thing that distinguishes these from absolute catastrophies is a matter of degree. Our infant mortality problem in this country is a testament to the relative catastrophic problems. Women who cannot afford prenatal care and children who cannot afford in their infancy periods access to primary care from horrendous catastrophes. We urge this committee to do several things.

First, it should extend the Bradley-Waxman legislation, introduced earlier this year, to include all children under the age of 18, not just under the age of 8.

The incremental cost of adding an 8-to-18 companion is very modest.

Second, Congress should mandate coverage of all medicaid-eligible children under the Federal poverty level. That was established as an option last year. That should not be an option.

Third, with respect to prenatal services, unfortunately the cost of mandating medicaid coverage or pregnancy care is one of the most expensive things that can be done, because of the cost of delivery. We think it should be done. But in the interim we suggest that at the minimum, Congress should swiftly appropriate an extra $30 million in funding for community health centers and an additional $75 million for Title V to cover some of the costs of maternity care.

[The prepared statement of Ms. Rosenbaum follows:]

REPARED STATEMENT OF SARA ROSENBAUM, DIRECTOR, HEALTH DIVISION, CHILDREN'S DEFENSE FUND, WASHINGTON, DC

Mr. Chairmen and Members of your Committees:

The Children's Defense Fund (CDF) is pleased to have this opportunity to testify today regarding catastrophic health costs among children. CDF is a national public charity which engages in research and advocacy on behalf of the nation's low income and minority children. The issues on which CDF works include child health, child welfare, child care, education, job training and employment, and adolescent pregnancy prevention.

For fifteen years, CDF's health division has engaged in extensive efforts to improve poor children's access to medically necessary care, including both primary and preventive services, and medical care requiring the most sophisticated and costly interventions currently available.

Both ends of the medical care spectrum -- preventive and intensive -- are vital to the health and well-being of children. Comprehensive primary care, including health exams, followup treatment, care for self-limiting illnesses and impairments (such as influenza or strep), and vision and dental care, is a fundamental necessity for virtually all children. Moreover, about one in five children suffers from at least one mild functional impairment such as asthma, a correctable vision or hearing impairment, or a moderate emotional disturbance and thus requires ongoing basic medical attention.

Additionally, about four percent of all children (a figure which by 1979 was more than double the percentage reported in 1967)[1] suffer from one or more chronic impairments with a loss of functioning. Included in this group are children suffering from degenerative illnesses such as cystic fibrosis, multiple handicaps and major orthopedic impairments. About two percent of all children suffer from one of eleven major childhood diseases including cystic fibrosis, spina bifida, leukemia, juvenile diabetes, chronic kidney disease, muscular dystrophy, hemophilia, cleft palate, sickle cell anemia, asthma and cancer.[2]

Finally, nearly 7 percent of all infants are born at low birthweight (weighing less than 5.5 pounds) each year.[3] Virtually all will require some additional medical services. Moreover, about eighteen percent of all low birthweight infants or

some 43,000 infants weighing less than 3.3 pounds at birth, will require major medical care during the first year of life. Many will require ongoing care throughout their lives.[4] Low birthweight infants are also at three times the risk of developing such lifelong impairments as autism, cerebral palsy and retardation.[5]

Fortunately, most children, even children with impairments, require relatively modest levels of health care. Only about five percent of all children incur annual medical costs in excess of $5,000.[6] However, both groups of children -- those will relatively low-cost medical care needs and those with high cost problems -- can be considered catastrophic cases, in either relative or absolute terms.

A. **"Relative" Catastrophic Needs Among Children**

For low income uninsured families, even routine child health needs can result in catastrophic expenditures if the term "catastrophic" is measured in relation to a family's overall income. In 1984, nearly one in every five children, and one in every three poor children, was uninsured.[7] (Table I) Additionally, one in six women, and one in three poor women, of childbearing age, was completely uninsured.[8]

Children under 18, who comprise 25% of the under-65 population, constituted over one-third of the uninsured in 1984.[9] Three quarters of all uninsured children have family incomes below 200 percent of the federal poverty level,[10] and the vast majority (between 66 and 75 percent) live in working families.[11]

Low income families, when confronted with even normal child health expenditures of several hundred dollars per year face insurmountable health care barriers. As a result, uninsured low income children receive 40 percent less physician care and half as much hospital care as their insured counterparts.[12]

There are two main causes of children's lack of health insurance. They are: the major gaps in the employer-based health insurance system; and the failure of Medicaid, the nation's major residual public health insurance program for children, to compensate for these gaps.

1. **The Private Health Insurance System Is Leaving More Americans Uninsured**

Our nation relies primarily on private health insurance to meet much of the health care costs of the working-age population and its dependents. Most of this private insurance is provided as an employment-related benefit.

Employer-sponsored health care plans are the single most important source of private health care coverage for Americans younger than sixty-five. In 1984, over 80 percent of all privately insured American children were covered by employer plans.[13]

Traditionally, employers have paid much or all of the cost of premiums for coverage of their employees (and frequently some or all of the cost for dependents). The costs of this insurance are held down because it is purchased on a group basis, and because the pool of employed persons excludes many nonworking Americans who tend to have the most health problems, including the elderly, the disabled, and those who are unemployed because they are ill.

The employer-sponsored health insurance system works fairly well for families headed by parents who are employed in jobs with good fringe benefits. It meets much of the cost of major health care expenses for employees and, to a lesser but considerable extent, their spouses and children.

But the system never has worked well for millions of low- and moderate-income families. First, it obviously excludes families with no currently employed members. Second, the system also excludes members of families--usually at the lower end of the wage scale--headed by parents whose employers do not offer their employees health insurance coverage as a fringe benefit. For example, 30 percent of all employers who pay the minimum wage to more than half their work force offer no health insurance.[14] The system excludes those children whose parents' employers either do not offer coverage to their employees' dependents or offer it only at an unaffordable cost. As a result, a child living in a poor working family is only about half as likely to have private insurance as a similarly situated non-poor child.[15]

There is every indication that these gaps in private insurance coverage are growing, not shrinking. First, as children increasingly live in single-parent headed families, there is a greater likelihood that they will be without private insurance coverage. Children living in single parent households are three times more likely to be uninsured than children living in two-parent households.[16]

Moreover, the United States is witnessing a major shift in the type of jobs the economy provides, away from job growth in the manufacturing industries and toward growth in the service

sector. Manufacturing jobs generally have greater levels of employer-paid fringe benefits, particularly health insurance. Service jobs, by contrast, are generally lower-paying and often part-time. These jobs, even if full-time, are significantly less likely to provide health insurance.[17] To the extent that the American economy continues this shift, we may be witnessing the inexorable collapse of the employer-based insurance system and the resulting disinsurance of the middle class and their families over the long term.

Even employers that do offer health insurance have taken substantial steps in recent years to reduce their expenditures by cutting back on the amount that they will pay for their workers' coverage. One-third of employers reported in a recent nationwide survey that they had reduced contributions to to their workers' (or their workers' dependents) annual insurance premiums, thereby increasing their workers' share of premiums.[18] This has made it more difficult for workers earning lower wages to continue insuring either themselves or their dependents. Between 1982 and 1983 alone, the proportion of employees with family coverage who were required to pay part of their premium cost rose from 40 percent to 50 percent.[19] In 1980, even before this shift, nearly one out of five employers contributed nothing toward workers' premium costs for coverage of dependents, leaving payment entirely up to employees.[20]

Employees earning low wages cannot afford to participate in their insurance plans if their share of the premium payment is high. Even in 1980, prior to recent cutbacks, employers, on average, paid only 75 percent of their employees' premium costs.[21] An employee enrolled in an employer-based group insurance family coverage plan requiring a 25 percent employee contribution, would have to pay as his or her share of the monthly family premium--about $62.50 on average. This represents 11 percent of a low-income employee's gross pay. The employee's share of the cost of family coverage is thus unaffordably high for workers earning low wages, forcing them to leave their dependents uncovered.

As a result, children in poor working families are even more likely than their parents to be uninsured. While 60 percent of poor working adults have some private insurance, only about 50 percent of children in poor working families do.[22] It has been estimated that more than 27 percent of all children who are

uninsured live with a parent who is insured.[23]

2. **Medicaid, the Major Public Insurance Program for Families with Children, Is Covering Fewer Children**

Medicaid, enacted in 1965, is the nation's largest public health financing program for families with children. Unlike Medicare, which provides almost universal coverage of the elderly without regard to income, Medicaid is not a program of universal or broad coverage. Rather, it is based on need. Eligibility depends on having extremely low income.

Because Medicaid is fundamentally an extension of America's patchwork of welfare programs, it makes coverage available primarily to families that receive welfare. With a few exceptions (including pregnant women and children younger than five with family incomes and resources below state-set Aid to Families with Dependent Children levels), individuals and families that do not receive either AFDC or Supplemental Security Income (SSI) are categorically excluded. For example, a family consisting of a full-time working father, mother, and two children normally is excluded from Medicaid even if the father is working at a minimum wage job with no health insurance and the family's income is well below the poverty line. Moreover, even though states have had the option since 1965 to cover all children living below state poverty levels regardless of family structure, as of December, 1986, 20 states still failed to do so.[24]

In addition to these restrictive eligibility categories, Medicaid excludes millions of poor families because of its financial eligibility standards, which for most families are tied to those used under the AFDC program.[25] In more than half the states, a woman with two children who earns the minimum wage (about two-thirds of the federal poverty level for a family of three in 1986) would find that she and her children are ineligible for coverage.[26] By 1986, the combined impact of Medicaid's restrictive categorical and financial eligibility standards reduced the proportion of the poor and near-poor covered by the program to only 46 percent--down from 65 percent a decade earlier.[27]

As a result of improvements enacted by Congress in 1984 and 1986, many previously uninsured low-income pregnant women and children will be aided.

- The Deficit Reduction Act of 1984 mandated that states provide Medicaid coverage to all children younger than five with family incomes and resources below AFDC eligibility levels.

- The Deficit Reduction Act of 1984 and the Consolidated Omnibus Budget Reconciliation Act of 1986 together mandate coverage of all pregnant women with income and resources below state AFDC eligibility levels.

- The Sixth Omnibus Budget Reconciliation Act, passed in late 1986 permits states at their option to extend automatic Medicaid coverage to pregnant women and children under age five with incomes less than the federal poverty level but in excess of state AFDC eligibilty levels.

If fully implemented in every state, these amendments will reduce by 36 to 40 percent the number of uninsured pregnant women and young children nationwide.[28]

However, even if fully implemented, these new laws will not compensate for Medicaid's growing failures. Medicaid still does not reach low-income children over age five in twenty states. Nor do these new laws aid the millions of uninsured, nonpregnant, poor parents, whether they are working or unemployed. Moreover, these recent improvements are unlikely even to offset the years of stagnation and erosion that Medicaid has experienced.

In FY 1985, Medicaid served 10.9 million children younger than twenty-one--more than 400,000 fewer than were served in Fiscal 1978.[29] This drop occurred despite the fact that Fiscal 1985 was the first year that the 1984 Deficit Reduction Act amendments were in effect, and it followed enactment by about a dozen states of additional optional Medicaid child coverage improvements. Finally, this decline occurred even though the number of children in poverty rose from 9.7 million to more than 12.5 million over the same time period.[30]

The primary causes of declining Medicaid coverage include stagnation in Medicaid's financial eligibility levels, and, beginning in Fiscal 1982, a virtual exclusion of poor working families from the program.[31] Even in 1977, a child living in a poor working family was 1.8 times more likely to be completely uninsured than one living in a poor, non-working family.[32] This figure has undoubtedly grown.

3. **Remedying the "Relative" Catastrophic Health Care Problem**

If the "relative" catastrophic health care problem is to be remedied, it is essential that the percentage of children with health insurance be increased. This might be accomplished by requiring all employers to offer health insurance, as Senator Kennedy has proposed, or by expanding Medicaid, as Senator Chafee is now preparing to propose, to allow states to offer coverage to any individual or family with income below 200 percent of the federal poverty level or any person excluded from private insurance because of a preexisting condition. We strongly

support both measures, which would complement each other.

At a minimum, however, we believe that any catastrophic health package produced by Congress this year should do the following, in order to reduce the number of poor children facing "relative" catastrophic health costs:

- Mandate state coverage under Medicaid of all children under age five living below the federal poverty level, to be phased in on a year-by-year basis beginning in Fiscal 1988. Such coverage is now optional.

- Mandate state Medicaid coverage of all children under age 18, and 18-to-21-year-olds in school, jobs, or job training programs, whose family income and resources do not exceed their states' AFDC eligibility levels. As noted above, the 1984 reforms extended such mandatory coverage to children under age 5 but left uncovered children ages 5 to 18. Legislation recently introduced by Congressman Waxman and Senator Bradley (H.R.1018 and S.422 would increase this age limit to age 8. We recommend a further increase to age 18 (and to 21 in the case of older children enrolled in school, jobs, or job training programs), with a phase-in of all such newly eligible children over age five by 1992.

- Provide states the option of extending Medicaid to any child under age 18 (and any 18-to-21 year-old in school, job or job training) with family income below the federal poverty level but over the AFDC eligibility level. Legislation passed in 1986 by Congress creates this new option but terminates coverage at age five. The Waxman/Bradley legislation would raise the age limit to age 8. We recommend that the age limitation be increased as outlined above.

- Increase funding for Community Health Centers by $30 million, as proposed by Congressman Waxman and Senator Kennedy. This would increase by nearly 200,000 the number of low income pregnant women who receive comprehensive prenatal care. Each dollar spent on such care reduces by over $3.00 the amount needed to care for low birthweight infants by reducing the number of infants born too soon or too small.

- Provide an additional $79 million to the Title V Maternal and Child Health Block grant in Fiscal 1988. In 1986 Congress increased the authorization for this program to $553 million in Fiscal 1987 and $557 million in Fiscal 1988. The program is still funded at 1986 level of $478 million, however. Title V is an essential source of funding for low-income uninsured pregnant women and children.

B. **"Absolute" Catastrophic Costs Among Children**

In addressing "relative" catastrophic health problems among children by expanding the number of children with health insurance, Congress would go a long way toward remedying children's absolute catastrophic needs, which arise in the case of severe illness or disability. However, it is evident that normal levels of insurance are inadequate in the case of severly catastrophically ill children -- that is children with more than five thousand dollars a year in health care costs.

Contrary to traditional notions of health insurance as providing protection against grave health risks, over time the nation has developed public and private health insurance systems

that are designed to meet normative, rather than catastrophic, medical care needs. Both public and private health insurance systems have developed myriad ways to limit their exposure for high-cost illnesses and disabilities in favor of providing subsidies for more routine and normative health needs. For example:

- Of all employers responding to a major health insurance survey conducted in 1986 73% indicated that their plans exclude coverage of preexisting conditions.[33] More plans now also contain riders that exclude coverage of certain conditions that may develop among enrollees, such as cancer.

- Only about 75 percent of plans offered by medium and large-sized firms between 1980 and 1985 contained protections against huge out-of-pocket costs borne by enrollees in the event of catastrophic illness.[34]

- Only 67 percent of mid-and-large-sized firms offered extended care benefits between 1980 and 1985, and only 56 percent offered home health benefits.

- In 1977 only 8.3 percent of all children had unlimited private coverage for major medical benefits, and one-third had coverage for a quarter million dollars of care or less.[36]

- Fourteen state Medicaid programs place absolute limits on the number of inpatient hosptial days they will cover each year, with some states limiting coverage to as few as 12-15 days per year.[37] About an equal number place similar limits on coverage of physicians' services. Others place strict limitations on such vital services as prescribed drugs and diagnostic services.

- Finally, both Medicaid and private insurance frequently fail to cover extended home health and related services (including such non-traditional items as home adaptation). When such coverage is available, it may be provided on a case-by-case exception basis.

The issue of whether private and public insurance should be required to meet more than normative patient needs is exceedingly complex, particularly since so many Americans are uncovered for even basic health needs. We think that both sets of need should be met, but achieving this goal will entail a major longterm effort and a large commitment of funds.

A key question is how to attain a catastrophic level of public and private insurance protection for the under-65 population. This could be done by amending federal tax laws, the Employer Retirement Income and Security Act (ERISA), Medicaid, to mandate catastropic coverage by all public and private payors or to require contributions by all public and private insurers into a catastrophic protection bill pool. Structually we favor a catastrophic mandate rather than a high risk pool, because pool premiums are unaffordable and because we believe that it is preferable for all payors to automatically offer such coverage.

However, mandating absolute catastrophic protection for the under-65 population is far more complex than in the case of

Medicare. Unlike Medicare, there is no single insurance system for the under-65 population and no political consensus on how to broaden the existing payor system to include at least some protection against major catastrophes. Therefore, the debate over modifying insurance mechanisms to protect against catastrophes facing younger Americans is an essential but longterm one.

In the short-run, Congress might consider providing some incremental relief for the small number children facing major catastrophic illnesses. This could be accomplished by creating a fund to be administered by state health agencies (perhaps by the agency administering the Title V Maternal and Child Health Block grant program for children with special health care needs). Such a fund might assist families whose children incur annual out-of-pocket medical expenses in excess of $5000 or 10 percent of their income (whichever is higher), either because the family is uninsured or has exhausted existing its private or public coverage or does not have appropriate coverage. Families whose children have high medical costs could be provided with an additional amount of funding each year, to be spent in accordance with individually developed case plan which emphasizes community-based care but which is flexible enough to meet a wide range of outpatient and inpatient needs.

Two major elements would be essential for this type of supplementary program to succeed. First, state health agencies could not discriminate on the basis of diagnosis, as is currently the case under Title V Programs for Children with Special Health Care Needs (formerly known as Crippled Children's Services and other diagnostically-related mental health or developmental disability programs. Because existing public programs for ill or disabled children tend to be tied to certain diagnoses, major illnesses such as cancer, leukemia, cystic fibrosis and asthma are frequently uncovered.[38]

Second, the eligibility standard under this type of supplementary catastrophic program should use a threshold out-of-pocket expenditure test rather than a gross family income test to determine children's eligibility for assistance. Currently, many state health programs for children with special needs place upper income limits on families' eligibility for subsidized specialty services. Since the purpose of this new program is to aid families on the basis of their children's excessively high uncovered medical costs the eligibility test should be based on

whether incurred out-of-pocket expenses exceed some absolute threshold, such as $5000 or 10 percent of a family's income. Moreover, a far different asset test should be used, so that families can retain sufficient resources to provide for their other children, as well.

In conclusion, any catastrophic approach for children must address both their relative and acute catastrophic needs. In the immediate future, we recommend expanding Medicaid to reach more poor children and the development of a supplemental funding program to aid families whose children have absolute catastrophic needs.

FOOTNOTES

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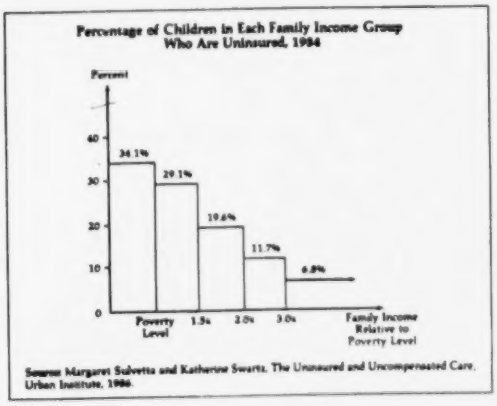
TABLE I



Chairman MILLER. Thank you.
Dr. Battle?

STATEMENT OF CONSTANCE U. BATTLE, M.D.

Dr. BATTLE. Chairman Miller, I am a Trustee of the National Association of Children's Hospitals and Related Institutions, and Medical Director and CEO of the Hospital for Sick Children, which I'd like to tell you about today.

At the hospital, we see the impact of chronic illness on the children and on their families daily, as they live out the 500,000 minutes of each year.

I'm not an expert in high technology care, in the acute care, of chronically ill children. But I would like to speak here to the transitional care required after the newborn intensive care unit, to integrate these children back into their families and into the community.

Our hospital, located in Northeast Washington, has 80 beds. Many of the babies there are born prematurely and no longer need the high intensity of an acute hospital. But they are still too sick to go home.

The average length of stay of a baby with bronchopulmonary dysplasia, which is a chronic lung disease of prematurity, is 6 months, but some of our babies stay over a year.

The annual cost of caring for these children is up to $182,000, or nearly $500 per day.

Mr. Chairman, 96.5 percent of our patients receive Medicaid benefits. Many of them are poor. Fourteen percent of our children have either exhausted their coverage or have insurance that does not cover the transitional care that we provide.

Let me mention briefly two patients at our hospital and the kind of care they need.

Jimmy W was a 5-month-old baby born prematurely who had been in an acute care hospital intensive care unit for 5 months. He came to us with a tracheostomy and that chronic lung disease, BPD, and was admitted to HSC for skilled respiratory care, developmental stimulation, and family teaching.

Our multidisciplinary treatment team taught Jimmy's mother and grandmother suctioning, chest physical therapy, tracheostomy care, rescuscitation techniques, oxygen administration, aerosol treatments, nutritional planning, and developmental stimulation techniques.

After a stay of 9 months, discharge preparations included referral to a day care program for infants with special needs and arrangements for follow-up by home care health team.

Jimmy now lives at home with his mother and attends a day care program.

The second patient, 7-year-old Rene B, lived with her family in a rural area of Virginia. She had malformations of her spinal column with associated neurologic disorders and needed a series of reconstructive surgeries.

In between each of three surgical procedures, Rene was admitted to the Hospital for Sick Children for intervals of progressive therapy, cast care, and training in the activities of daily living.

She was discharged after 5 months to her family with increased independent functioning and arrangements to return to her school.

These case studies are of children who survive today, and are able to live with their families. But they would not have in the past. These children illustrate clearly the changing and enhanced needs of a pediatric, long-term care population.

I welcome this discussion and consideration of catastrophic illness. I hope very much that it will lead to the development of creative, comprehensive programs to both care for these children and provide predictable financing for their future.

Thank you for giving me this opportunity.

Chairman MILLER. Thank you.

Dr. BATTLE. I'd like to introduce Mr. Robert Sweeney, President of NACHRI.

STATEMENT OF ROBERT H. SWEENEY

Mr. SWEENEY. Thank you, Dr. Battle and Mr. Chairman. I'll just make a few very brief remarks if I may.

We have 94 children's hospitals throughout the country and we've heard and seen the types of cases that these institutions treat.

We had a meeting last week for our membership in which we discussed this whole problem of catastrophic illness expense and children. One administrator of a children's hospital who attended that meeting presented nine cases, youngsters who had been admitted anywhere from one to seven times, and their total bills for those periods of hospitalization was over $5 million.

And the families had paid on their behalf $2.7 million leaving the families and the providers to deal with the residual of about $2.5 million. Five of the patients were medicaid patients. In that State medicaid paid only $41,000 toward total charges of over $2 million. The interesting thing is, one child in that cohort of nine had all his bills paid. He had a multitude of medical problems. But in this case a blessing in disguise. He had a renal problem and so was covered by medicare as part of the end stage renal disease program.

But there's only 2,000 youngsters in the country who have the coverage of medicare through the end stage renal disease program. So we have to find another vehicle for use other than medicare when we talk catastrophic illness in children.

We've looked at admissions in children's hospitals and our finding is that 1.35 percent of the patients have bills of over $50,000 and that accounts for 26 percent of the total charges for those patients. These cases average $105,000 and they stay in the hospital perhaps three months.

Half of these cases are newborns. They are either premature or they have birth defects.

If I may, Mr. Chairman, I have some detailed information on these studies that I would like to put in the record. And I would also like to submit the position paper that our association has developed on this whole question of catastrophic illness expense in children.

[See appendix 2 for material submitted by Mr. Sweeney.]

Mr. SWEENEY. We have identified really three causes of catastrophic illness expense for families.

First is the traumatic situation. We saw examples of that this morning. The child with serious burns, or trauma, or perhaps a liver transplant, heart transplant.

And frequently enough these cases then slide into what we would categorize as the second group, and that is severe, chronic conditions in children.

But Mr. Chairman, there is one other type of catastrophic illness that we see and experience so frequently in children's hospitals and that is what we call the first dollar catastrophe.

That is where the family has no resources whatsoever to even avail themselves of basic care. Those are the kids that we see at 3 in the morning in the accident rooms with chronic ear infections which left untreated or treated in an episodic way can lead to more serious problems. And that's the case of these premature babies that we see, so many of them from young mothers who don't have adequate protection and have had no adequate prenatal care.

So many of those high cost babies could be prevented with a few dollars spent up front as I know you are aware.

We think you mentioned earlier, Mr. Chairman, the question of the Brazilian banks. And we think that has a direct influence on what is going to happen in meeting some of the problems, social problems we have in this country. But we do think a great deal could be done in the private sector.

And we have some proposals that are contained in our full statement here.

First, Senator Kennedy is going to introduce legislation requiring employers to provide minimum insurance which would cover prenatal services and primary services for children within insurance pools to assist small employers. We think that is an important step to get first dollar coverage in place.

We would urge that we facilitate individual choice of basic and catastrophic coverage through State risk pools and tax incentives. And we see, Mr. Chairman, as a possibility of a tax incentive, that the legislation read that unless an employer provides a catastrophic rider on his basic policy it's not a tax deductible business expense.

On the other hand, we think it would be appropriate where families can afford to do so if employed parents do not cover their dependents with their insurance, that the employee be taxed on the dollar value of the insurance that he's had provided to himself or alternatively, we would suggest that there be a deduction in the standard exemption allowed to, for each youngster if the family did not meet its responsibility and cover those youngsters in the group insurance plan available to the employer.

We support very much the position that the Children's Defense Fund takes, that mandates medicare coverage for pregnant women, and children under age 6, who are below the Federal poverty level and standardized medicaid coverage for mandated services.

Mr. Chairman, that's a big bite, as you well know. In some States, unfortunately, among our 50, if you had a meal in a week you don't qualify for some of the health programs.

But that, we think, needs to be done so that we talk about America's children, not Wisconsin's children or Texas' children or Mississippi's children.

And we do believe that any studies that move forward a federal initiative, any studies of catastrophic illness, that children and youth should have a high place on the agenda to determine the further needs of this very important segment of our population.

And I thank you, sir, for the opportunity.

[Prepared statement of Mr. Sweeney follows:]

PREPARED STATEMENT OF ROBERT H. SWEENEY, PRESIDENT, NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS AND RELATED INSTITUTIONS, ALEXANDRIA, VA

Mr. Chairman, I am Robert Sweeney, President of NACHRI, the National Association of Children's Hospitals and Related Institutions. On behalf of our 94 member institutions, I would like to thank you and congratulate you for holding this hearing on catastrophic illness expense and children.

NACHRI's mid-year meeting focused on the issue of catastrophic illness expense and children, and we are delighted that the debate is beginning to expand to include, indeed recognize, that all Americans, not just the elderly, are at risk for catastrophic illness expense.

Catastrophic illness expense is a problem for children and their families. While catastrophic illness is rare in children, the financial consequences for a family can be devastating.

At our meeting last week, one of our children's hospital administrators spoke of nine children in his hospital whose bills amounted to over $5.0 million. The hospital received $2.7 million dollars. Five of the patients were Medicaid patients. In that state, Medicaid paid only $41,400 toward total charges of over $2 million. The only child whose bills were fully paid had end stage renal disease and thus was protected by Medicare. Only 2000 of the nation's 60 million children have Medicare protection, through the end stage renal disease program.

A recent NACHRI study of 85,000 admissions to children's hospitals shows that only 1.35 percent had charges over $50,000. However, those cases accounted for 26 percent of the total charges for the children's hospitals. The average charge for these cases was $105,000, and the length of stay was about three months. One half of these cases were newborn babies, either premature or with birth defects.

I would ask permission that this study and the summary of nine catastrophic cases be submitted to the hearing record.

I would also ask to submit the NACHRI position paper on catastrophic illness expense and children, and briefly summarize the four components of a comprehensive solution for children.

- Require employers to provide minimum insurance which covers prenatal services and primary services

for children, with insurance pools to assist small employers.

- Facilitate individual choice of basic and catastrophic coverage through State risk pools and tax incentives.
- Mandate Medicaid coverage for pregnant women and children under age 6 who are below the federal poverty level, and standardize Medicaid coverage for mandated services.
- Include children and young adults in federal demonstration projects and studies of catastrophic insurance coverage.

I would now like to yield to Dr. Constance Battle, Chief Executive Officer and Medical Director of The Hospital for Sick Children here in Washington, and a trustee of NACHRI, to speak on the long-term and chronic care aspects of catastrophic illness in children.

Thank you, Mr. Sweeney. At The Hospital for Sick Children, we see the impact of catastrophic illness on children and their families every day. I am not an expert in the high technology, acute care of catastrophically ill children, but I would like to speak to the transition care required after the newborn intensive care unit to integrate these children into their homes and communities.

My hospital, located in Northeast Washington, has 80 beds. Many of our patients are babies born prematurely who no longer need the intensive care of a general hospital, but are still too sick to go home. The average length of stay for a baby with bronchopulmonary dysplasia (a chronic lung disease) is six months, but some of our patients must stay for over a year. The annual cost of caring for these children averages $182,000.

Mr. Chairman, 96.5 percent of our patients receive Medicaid benefits. Many of them are poor, but 14 percent of them have either exhausted their coverage or have insurance that does not cover the transition care we provide. Now let me mention briefly two patients at our hospital, and the kind of care they need.

Jimmy W. was a five month old baby born prematurely who had been in a hospital intensive care unit since birth. He came to us with a tracheostomy and bronchopulmonary dysplasia, and was admitted for skilled respiratory care, developmental stimulation, and family teaching. Our multidisciplinary team taught Jimmy's

mother and grandmother suctioning, chest physical therapy, tracheostomy care, cardiopulmonary resuscitation procedures, oxygen administration, aerosol treatments, nutritional planning, and developmental stimulation techniques. After a stay of nine months, discharge preparations included referral to a day program for infants with special needs and arrangements for follow-up by a home care team. Jimmy now lives at home with his mother and attends a day program.

Seven-year-old Rene B. lived with her family in a rural area of Virginia. She had malformations of the spinal column with associated neurological disorders, and needed a series of reconstructive surgeries. In between each of three surgical procedures, Rene was admitted to The Hospital for Sick Children for intervals of progressive therapy, cast care, and training in activities of daily living. Rene was discharged after five months to her family with increased independent functioning and arrangements for her return to school.

These case studies of children who survive today and are able to live with their families, but would not have in the past, illustrate clearly the changing and enhanced needs of a pediatric long-term population. I welcome this discussion and consideration of catastrophic illness, and hope very much that it will lead to the development of creative and comprehensive programs to both care for these children and to provide predictable financing of that care. Thank you for giving me the opportunity to speak on this issue.

STATEMENT OF MICHAEL MORRIS

Mr. MORRIS. Good afternoon. I am here today testifying on behalf of the Consortium of Citizens with Developmental Disabilities, a coalition of over 80 national consumer and provider organizations. I also am here today to testify on behalf of the United Cerebral Palsy Institution, a national network of community based providers of services to persons with severe disabilities with approximately 180 affiliates in 45 States across the country. Collectively, UCPA spends about $200 million a year to provide vital services to persons with severe disabilities.

Many of these organizations have, for some time, supported the development of a national health insurance health care mandate. However, we are seeing that much of the discussion towards this goal does not adequately incorporate and in fact, pointedly excludes the concerns of children and adults with disabilities and that those we represent will be left out as progress is made on the various proposals.

Severely limited access to appropriate health care and related services in the private sector have devastated the lives of many individuals with disabilities and their families. All too frequently they have been forced to bankrupt themselves in an effort to meet ongoing health care costs often leading to unnecessary and expensive institutionalization of individuals, specifically children with disabilities.

The long-term care costs of disabilities and chronic illness can be catastrophic. Of the catastrophic illness insurance proposals circulated to date, it is evident that only a small percentage of elderly medicare beneficiaries will minimally benefit. Of the 37 million Americans without health insurance, many of whom have disabilities, chronic illnesses, and their families, none will benefit from these plans.

The fact is 36 million Americans have disabilities. 3 percent of all children have severe disabilities with 11 percent of these children having severe chronic medical problems requiring continuous health care.

UCPA Governmental Activities Office is often asked the cost involved in providing support for persons with cerebral palsy and similar disabilities. Since no figures to our knowledge are available, approximately 18 months ago, UCPA, with input from a number of professionals, prepared a cost survey questionnaire. A letter was sent to about 50 affiliates in 15 States in various geographical areas asking if they would participate by helping distribute the questionnaire to consumers and their families.

About 600 questionnaires were reported distributed. Of those distributed, 239 responses were received from 12 of the 15 States.

The design of the survey was intended to factor out costs which nondisabled children do not share. In describing these costs, it is important to remember that the cost of raising a child with a disability depends on variables in each individual case, such as the severity of the impairment and the money available to the family to help the child.

One of our families in Northern Virginia has a 4-year-old boy with cerebral palsy. In talking with them, I learned more about the

exorbitant costs of specialized equipment and assistive devices. They spend over $10,000 a year for physical therapy, occupational and speech therapy for their child and then must purchase equipment prescribed for them such as wheelchairs, braces, crutches and special adaptive devices. Special therapeutic devices, such as inhibitive cast devices to stretch high tone muscles, devices to aid in standing to allow for weight bearing so hips can develop properly, special chairs, strollers, potty seat, eating utensils and even special learning devices can cost hundreds of dollars as conventional models will never do.

Communication devices which provide many of our children and adults the ability to effectively communicate, seldom provided by an outside source because they are not considered medically necessary, are often beyond the means of families. Constantly replacing equipment and repairing it as the child grows and as the equipment wears out is a continual drain on family resources. One parent from Texas says her child goes without doctor ordered equipment. She cannot afford it, so it is not an expense.

During one month for well care and medical maintenance, a family described this list of doctors visited: an orthopedist, a developmental pediatrician, a psychiatrist, a doctor of physical medicine, opthalmologist and a neurologist.

Families usually bear the entire cost of removing architectural barriers for their disabled family member. If a family can afford to build an accessible home, the cost is great. Many families are only able to build a ramp so the child can get into the house or widen the doorways a little so a wheelchair can pass through. Full accessibility needs are very often not met. Families make do with what they can afford.

Special transportation costs are also borne exclusively by families. Taking a disabled child to and from beneficial programs and therapies result in needs for special transportation. Costs range from a special belt for the car to specially equipped vans with wheelchair lifts. Electric wheelchairs, which many of our children need for mobility, are $5,000 and have a lifespan of 2 to 3 years. They often need to be repaired and many families go without a back-up chair. Many severely and moderately impaired participants in the survey indicated no special transportation expenses. This omission means in all likelihood that they have no transportation.

The average expenditure per year for special disability related expenses in our survey, excluding surgeries, is $5,282 per family. To raise a child to the age of 18, the cost would be $95,083. If surgeries are included in the averages, the cost is $7,035 per year or $126,631 to age 18. Add to this the $4,600 per year normal costs of raising a child as estimated in a report published by the Urban Institute entitled Investing in Children, The Estimates in Expenditures of Parents. By the time a normal child reaches the age of 18, the family has incurred expenses of $82,400. Add to this the $10,000 needed for raising a child with disabilities or chronic disease and the problem faced by parents is obvious. The disabled child has the same food, shelter, clothing and schooling needs as the normal child.

The cost of raising individuals we represent is long term not a one time surgical or catastrophic cost, but a continuous daily cost. The costs are just as intense, but the difference is that they are lifelong in nature. Families of moderate income frequently suffer more than low income families because they are ineligible for State or Federal help, yet they can't afford the large expenditures needed to help their children. A parent from Louisiana said they were penalized because they have a moderate income and chose to care for their child at home.

It is interesting to note that only 1 percent of respondents to the survey were able to bear the expense of supporting a disabled family member without outside help; 37 percent received government help in some form; and 11 percent of those received medicaid assistance.

Of the 239 survey respondents, 39 of the families received help from private employer furnished insurance plans and 11 percent were served by Blue Cross-Blue Shield.

Medicaid usually paid all costs. However, much of the care provided under the system is still tied to unnecessary restrictive settings at costs which usually exceed the cost of community based or home based care. One parent from California reported that her son is now in an institution at a cost of $1,400 per month. She said she could keep him at home for $700 per month, but funds are not available to them.

Although a cumbersome process, the waiver program has expanded the list of options states have to structure more cost efficient and effective care for children and adults at risk of institutionalization. For disabled children and adults, the waiver brought an expanded universe of possible community and home based services if states so chose the option. However, the need to show an offset in family based service costs and a difficult renewal process has hampered State participation in the program.

Within broad guidelines established by the Federal Government, States have flexibility in structuring their Medicaid programs and they in turn varied greatly from State to State. Frequently, Medicaid was only an option after the family divest themselves of their assets and reduce their incomes. Some families have to stop all financial support for their disabled child so he or she would be found eligible for Medicaid.

Those families eligible for Medicare had even more serious limitations. First, it has been structured primarily to be an earned benefit for elderly, former members of the labor force. Individuals who qualify for Medicare on the basis of disability are eligible only after a 24 month waiting period. Medicare recipients commonly require longer and more frequent periods of rehabilitation care. Inadequate access and waiting periods often result in decreased health status and costly hospitalization. The waiting period negates medical evidence supporting the importance and the cost effectiveness of early intervention.

Although Medicare has a uniform benefit structure, it particularly limits from coverage many of those items which are of greatest importance in the ongoing health care support for children and adults with handicaps, prescription medications, certain support maintenance therapies, numerous items of disposable and durable

equipment such as communication devices, hearing aids and environmental controls, extended rehabilitation services such as occupational and physical therapy.

In addition, individuals with disabilities are unable to assume the copayment and Part B premium, physician and other outpatient services requirements, for what is a limited system of care with no cap for out of pocket expenses, greatly reducing Medicare's potential effectiveness as coverage for people with disabilities.

Moreover, it is important to realize that a very small number of individuals with disabilities are served by Medicare and Medicaid. The Medicaid program provides health care to approximately 3 million persons with disabilities, only 60 percent of disabled children below poverty, and only 25 percent of disabled children overall. Medicare picks up another 3 million. However, at least 26 million Americans have disabilities.

Although more individuals with disabilities have better and more appropriate access to employment and more are working and able to pay for private insurance, they are still unable to obtain employer based coverage. In the UCPA survey, private insurance was found to be a supplement primarily for surgeries and direct medical costs without regard to medical maintenance or management of long-term needs of the disability of chronic illness. For example, a family in Atlanta bought what seemed to be adequate coverage. A year later, they had a child which developed epilepsy as a result of a childhood stroke. The family is facing $30,000 out-of-pocket expenses for neuro-surgery to control the seizures. The family is unable to purchase a better policy because of the preexisting conditions.

Some insurance companies were described as categorically excluding costs associated with cerebral palsy, Down syndrome, diabetes, mental illness, epilepsy and other disabilities assuming that total exclusion is more cost effective than community based management when in fact, inpatient or treatment crisis management of these conditions is by far the more costly of the options.

Full time employment for employer based benefits is a luxury not afforded to parents of disabled children. A hidden cost is the salary forfeited over the years because one parent must stay at home. One parent from New York said she quit work and stayed home for 15 years to care for her disabled child. At $15,000 per year, the family lost $225,000 in income. A mother in northern Virginia forfeits $30,000 annual teaching salary to transport her child to and from speech and physical therapy. Friends won't watch her child and babysitters are hard to find even for the few evenings she and her husband attend support groups.

Small business, the largest growing segment of the employment sector, frequently offer no health care coverage. When they do offer coverage, they are only able to provide limited, mostly acute care benefits, frequently with high deductibles or copayment requirements. The policies are frequently inadequate in their breadth to meet the needs of children with disabilities and chronic illness.

The intense, expensive and chronic support needs of a child with a disability means that the lifetime cap will be met early on these obtainable policies and, therefore, at some point access to necessary

care will be blocked. This is particularly true for medical technology dependent children and adults.

The expenditures and care needed for a disabled child brings pressure and costs to a family that cannot be measured in any survey. Constant care and frustration involved in raising a disabled child is a factor in the breaking up of families. Respite care and counseling are not luxuries to be afforded by a few, they are necessities for family survival. Many families show strength, resilience and resourcefulness when faced with these adversities. Their patience and love are amazing, but even the strongest of families admit that help is needed.

The expansion of health care options in both the public and private sector must be evaluated in the extent to which it can be strengthened to address the access, affordability and breadth of coverage concerns which I have laid out in this paper so far.

At a minimum, any employer based mandate must address primary and preventive care services and prescription medications. In the past few years, Congress has made significant strides towards assuring that certain vulnerable groups have access to preventive health care. However, there has been little change in the percent of women receiving late or no prenatal care. The incidence of low birth weight has shown little improvement nationwide. To continue to address this, the Maternal and Child Health Care Block Grant program must be funded up to the authorized level for fiscal year 1987 through the supplemental appropriations process currently underway in the House and be fully funded for fiscal year 1988. Full funding of this program is necessary to assure cost effective options for health care for at risk women and children, including children with special health care needs, and to provide the health delivery system structures necessary for States to opt for the Medicaid expansion approved last year through reconciliation process.

Appropriate coverage options for children and adults with preexisting conditions must be developed to stem the rising tide of individuals who find themselves medically uninsurable. Many of these people are children with disabilities and chronic illness.

Medicaid coverage should be available on a buy-in basis for people who have been denied health care coverage because of their preexisting condition and for people who have exceeded their maximum coverage under private insurance.

The existing systems are not perfect. Significant amendments are needed to both Medicaid and Medicare to address the comprehensive health care needs of children and adults with disabilities and chronic illnesses. CCDD commends your efforts to broaden the catastrophic insurance discussions to include children and will be available to help the committee.

Thank you.

Chairman MILLER. Thank you very much.

Mr. Sweeney, I guess the case is made, I asked it before, but if I look at your fact sheet here, and if 65 percent of Maryland's catastrophic cases are newborns, somehow we're not getting the job done, around prenatal care. I mean, with what we know can be done and what we're told constantly study after study, about the impact of proper prenatal care, that figure just does not need to be.

Mr. SWEENEY. Yes, sir. And it just seems terribly shortsighted.

Chairman MILLER. How do you organize this effort? I mean, we've done it in bits and pieces around various programs, but at some point, it seems to me that politically the hospital has to consider this. If that's the case, and if having just gone through where we're right in the middle of a tragic dumping case in my district, hospitals are going to be under pressure to render that service whether resources are there or not.

Because in the case of my district, the baby died, as it was moved to the county hospital. And not to be crass, but I think the hospital would have rather delivered the baby than face a lawsuit. Maybe that's what it takes. But it seems to me, just on the financial basis, hospitals, at some point, have got to campaign to let public policy people know that this is insanity to continue to accept the number of high risk pregnancies that you are required to because for whatever reason, society doesn't address those problems.

I know we have "healthy babies" and we have all of these campaigns, but, in the same media market, 65 percent of the catastrophic cases are newborns.

And that's a devastating figure.

The catastrophe is the prenatal care.

Mr. SWEENEY. Or the lack thereof. The catastrophe is the pregnancy, to begin with. The unplanned pregnancy. And they're very frequent in a young girl. That's where the catastrophe starts.

Then in our society, we tend to shun rather than to support that person. And then she goes without adequate care and the baby is delivered and transferred to an institution such as the Children's Hospital.

The cost of the infant in the neonatal intensive care unit in 3 days would more than have met a full program of prenatal care and delivery.

Chairman MILLER. I can get it down for you cheaper than that.

What's the second, would accidents be the second largest cause of catastrophic——

Mr. SWEENEY. Above a year of age.

Chairman MILLER. Above a year of age, which would be accidents in terms of number of children.

Let me ask you a question. One of the things that always worries me about this notion that we're just going to flip to a home health care industry is that there is no real industry out there in terms of the kinds of services and the numbers of trained people that we need to deliver these services. It reminds me a lot of when we closed state mental facilities in California on the basis that there was going to spring forth a community-based delivery system. Well, 20 years later, we're still waiting and it hasn't happened.

And I'm concerned here, too, that while the intentions are good by all of us in wanting children home where they can be taken care of by their families and participate in a family environment, if you were to mandate that, you wouldn't have available services as I see it right now. Is that accurate?

Ms. ROSENBAUM. I think there is a large deficit in the amount of long-term-home and community-based care services available.

Certainly there are children in institutions who might be able to come home or into a home like placement, if we had more flexible financing arrangements. But there is no doubt that first of all,

there would be a certain number of children who just could not come home, who would need a long-term institutional placement of one sort or another.

And second, that there would be children who could come home with a level of assistance that simply is not in place.

Now, it would be a tremendously useful thing were there a much expanded Crippled Children's Program in every State that had enough people either on its own staff or under contract in various institutions with expertise in this area who could perform the kinds of jury-rigging of systems that you hear these parents having to provide for themselves.

I mean, it's very difficult for a family to have to go negotiate with Traveler's Insurance about what it will or will not pay for.

Many children's hospitals do provide extensive assistance in fact, in day-to-day care and negotiations. That's sort of part and parcel of the service. It ought to be formalized, however.

There is no question that we do not have a system for everybody at this point, but between what we provide now and what we might be able to do, for example, with better financing, there could be a fair amount of improvement. But there is one other issue. And that is the children who cannot be brought home because their families do not have the financial means to bring them home.

As you heard this morning, it means a family having to give up usually having a two-wage-earner family in order for one of the wage earners to act as a case manager and an attendant and perform all the other necessary functions.

There is no reason why the SSI program could not pay for this. Right now a child is paid essentially $300 a month maximum under the SSI program.

If that program were to pay a much higher rate, for example, $2,500 a month, so that the home members in fact could be compensated for some of the services they furnished, it would be much more cost effective and it might make some of the placements more economically viable.

The absence of decent income maintenance for technology-dependent and other severely disabled children is a major barrier.

Chairman MILLER. Yes, Dr. Battle.

Dr. BATTLE. The health care providers aren't there, either. There are simply not enough nurses to provide care for that kind of——

Chairman MILLER. I think that was my point. I mean, there's an industry out there that's sort of fledgling and figuring out how you get in on this one to provide home health care and how you manage it and I guess there's a few big regional operations that see this as in fact a proprietary operation.

And I appreciate that. But I always get a little nervous when that and human services rub up against one another. And yet I think it's also essential. I mean, I don't mind the private sector being involved in this at all and I don't mind bidding out the care of young people, and you get decent care for that.

This notion that you're always going to get it for $3.27 an hour is just, you're not going to get anything. That's what I see certainly in working with the disabled. It's just not there on any kind of reliable basis. But also, if you were going to take out of the institutional setting the number of children that we desire to, I just don't see

that any real infrastructure is there so those families could have the body of service. Now, that certainly is not an argument for not doing it, because you should put that in place. I'm just trying to think of where we are in the scheme of things here.

Mr. SWEENEY. Mr. Chairman, if I could draw a parallel for you, and I don't hold up the end stage renal disease program as a paragon of virtue in our whole system of delivering health care. But I'm old enough in this business to recall before we had that program, we had committees in hospitals who decided who would go on dialysis and who would not.

There was no equipment, there was not adequate equipment and hospitals couldn't afford to buy that very expensive equipment at that time because there wasn't resource.

Now, the Congress in its wisdom decided this is repugnant. We don't have committees decide who lives, who dies. And so end stage renal disease was added to Medicare.

The key point is here the system was resourced. A predictable, dependable flow of resources for both patient and provider were provided and you very rapidly developed an end stage renal disease treatment capacity in this country.

And the same thing can happen with home care if there can be predictability.

But from what I read, the Congress has enacted expansion of home care under Medicare and the administration has been doing everything they can to take it away. And people are not going to commit to that type of program where the money is here today and gone tomorrow. We've got to have predictability.

And once it's predictable that resources will be there for families so the families can purchase adequate services, in the great American system the services will appear.

Chairman MILLER. Mr. Morris, you started to say something.

Mr. MORRIS. I was going to add a similar comment, that when I think of the experiences of some States in terms of attendant services, it often is a question of resources, of what comes first. You are never going to have the qualified personnel across the many disciplines that are necessary in terms of taking care of the needs of children with severe disabilities unless you put the resources there.

Chairman MILLER. I guess that's my concern. I don't want to belabor the point. But it seems to me if you take the premise of the hearing this morning, that there are simple impediments to receiving medical treatment in the home, that that's not enough, because that's not really the issue.

It seems to me it's more than the fact that like services can be performed in the home or in the hospital, because that's a very narrow definition of services.

In almost each and every one of the young people's cases today, the narrow service that they need to be medically reimbursed for you can say fine, let's do that in the home because it can be done.

But the total services that the family needs to continue to hold itself together and to move that child along to normal development is not even spoken to in most of these cases. It's just simply not there.

Because we don't consider it in terms of the kinds of services that are necessary for those young people, whether it's respite care

or transportation or counseling or all those things that we don't see as an attendant part of that disability.

Mr. MORRIS. Yet, within our Medicaid policy, and with the change that was made about 1973 in terms of the one little piece, one amendment made by Senator Bellmon at that time to create the ICFMR DD program, we are now spending $2.5 billion for children and adults if we will institutionalize them and give them 24 hour a day so-called active treatment, yet we don't have similar public policy——

Chairman MILLER. No. All I want to say is when we convert it from 24 hour a day active treatment that we convert it to 24 hour a day active treatment at home.

Mr. MORRIS. Absolutely.

Chairman MILLER. And there's a world of difference between what I think is going on, which is just to just say OK, you can medicate yourself at home, and we'll reimburse you for the medication and you can take care of your son at home and we'll reimburse you for the medical cost; 24-hour a day active treatment is more than just medical costs.

I'd just like there to be a fair conversion. I still think the cost is much lower but in terms of the kind of treatment you want I don't want to lose the——

Mr. MORRIS. What I am speaking of goes far beyond medical costs. It's the whole umbrella of social service supports that are needed by individuals.

Ms. ROSENBAUM. I think it's also very important to remember the education amendments that passed last year because those are going to set in motion if they work properly, the reshaping of services that are available in the community, starting in infancy.

It's very important now that health payers come in and begin to recognize that some of those services are both educational and health related and expand what they will pay for in order to underwrite fledgling, early intervention systems which includes a broad range of services that we think of as not health related but which of course go right to the survival of these children.

Chairman MILLER. That assumes that the argument at the local level has stopped at this point.

Ms. ROSENBAUM. The argument?

Chairman MILLER. In terms of how those services are going to be——

Ms. ROSENBAUM. Well, there's a long implementation road——

Chairman MILLER [continuing]. The child before they tell you how they're going to pay for it.

Ms. ROSENBAUM. I think that it is important though that the health payers get their feet wet at the same time. And they haven't done it at this point.

Chairman MILLER. Well, thank you very much for your time and your testimony.

[Whereupon, at 2:05 p.m. the hearing was adjourned.]

APPENDIX

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MOSS/PERCY REPORT HIGHLIGHTS THE SCANDAL OF NEEDLESS INSTITUTIONALIZATION OF CHRONICALLY ILL CHILDREN

Washington, D.C. - March 28, 1987: Senator Frank E. Moss, Chairman of the Board of the Caring Institute, the public policy arm of the Foundation for Hospice and Homecare, today released a report before an unprecedented joint hearing of the House Select Committee on Aging and the House Select Committee on Children and Youth.

The reported entitled: "The Crisis of Chronically Ill Children in America: Triumph of Technology - Failure of Public Policy," is the result of two years research based in ten states: Arizona, California, Connecticut, the District of Columbia, Illinois, Maryland, Michigan, New York, Pennsylvania and Virginia, which account for more than fifty percent of all national expenditures on health care.

Simultaneously, the Institute previewed for the two Congressional Committees a half hour documentary soon to be released entitled: *"Suffer Not the Little Children"*, narrated by Ms. Susan Sullivan.

Both the report and the film examines what Senator Moss termed "a blight on the American conscience and the clear violation of the civil rights of the most vulnerable members of our society."

The report examines the unlikely but accurate fact that thousands of American children are needlessly institutionalized. They have been deprived of basic rights most Americans take for granted: an opportunity to be at home with their families and to develop to the full extent of their God-given abilities.

Senator Charles Percy, a member of the Board of Trustees, joined in releasing the report. He and Senator Moss each served eighteen years in the United States Senate during most of which they served respectively as ranking Republican and Chairman of the U.S. Senate Special Committee on Aging's Subcommittee on Long-Term Care.

"There is a good deal of talk now-a-days about the need to provide coverage for catastrophic health events and there is growing recognition that the major gap in our health care system is long-term care. As this report proves, long-term care is not something limited to the elderly, nor is it synonomous with nursing homes. It proves

conclusively that we have to find better ways to help families care for their chornically ill at home--young and old alike. I am proud that our organization can serve as the bridge to bring together the old and the young of our nation as symbolized by this unprecedented joint hearing between the House Committees on Aging and Children and Youth," said Senator Percy.

"Day after day, these children live a regimented, regulated existences, confined to rooms without windows, isolated from society. They spend months, if not years, under hot lights in tiny cribs never seeing the clouds, never having the chance to smell flowers, or hear a bird sing. They do not know what it means to play and for the most part, they do not know what happiness means," said Senator Moss.

"The crime that these youngsters have committed is to be born less than perfect in a society which prizes perfection. The worst offenders are kept in solitary confinement in total isolation. Their sentence often is for life."

Senator Moss said the sad part is that most of these children could be cared for at home. Their lives have been saved by modern technology and this same technology now has been miniaturized and made portable so that it can support the child at home for a fraction of the costs of comparable institutionalization.

"These youngsters are the victims of a failure in public policy. The only reason they are not cared for at home is that the policy has not been changed to keep pace with the changes in technology. A national policy which allows for the long-term care of chronically ill children must be developed immediately. This policy must be in concert with the best interests of the child, his family and of society. This policy should be based on care in the home and preserving the sanctity of the American family," said the Senator.

Following are other major conclusions reached in the context of this report:

1. There are approximately two million children in the United States who suffer from severe chronic illness. Many of these children are kept in hospital intensive care units or other institutions. Another ten million children are afflicted with some degree of chronic health impairment which inhibits daily functioning. Accident victims must also be added to the list. It is estimated, therefore, that from one to ten percent of the nation's children suffer from chronic problems of a moderate to severe nature.

2. The above figures are significant because a small minority of this nation's children currently account for approximately forty percent of all pediatric inpatient days in hospitals in the United States. Thus, while their numbers in one sense may seem small, chronically ill children account for an inordinate amount of the nation's health care resources.

3. A high percentage of the nation's chronically ill children were born premature. Modern technology has made it possible to save lives of infants who weigh two pounds or less. A few years ago a rough rule in medical science was that children were not likely to survive unless they weighed more then three pounds. A second large category is made up of children who were carried full term, but who are born with birth defects.

4. Most of the children fall into eleven categories of so-called "marker" diseases, including leukemia, cystic fibrosis, congenital heart disease, spina bifida, asthma, hemophilia, chronic kidney disease, juvenile diabetes, muscular dystrophy, cleft palate, and sickle cell anemia. A small but rapidly growing number of children are victims of AIDS.

5. The primary emotions of parents whose child suffers from birth defects or other anomalies are fear and frustration. The words most commonly used by parents to describe their reaction were: "We were terrified."

6. Most families want to have their children at home with them. Contrary to mythology, most families do not abandon their children if they are born with anomalies. They accept them and want to have them at home as part of the family unit.

7. Physicians are in agreement that it is possible to manage the care of most children at home--even complex cases involving multiple disabilities.

8. Physicians interviewed were in general agreement as to the criteria which must be met before a child can be discharged from an institution into a home care setting. First, the child must be medically stable. Second, the transfer to the home must offer the child an improved quality of life. Third, the transfer to the home setting must be an acceptable risk. The risks must be small enough to be offset by the advantages of having the child at home. Fourth, the family must be willing and able to take on most, if not all, of the child's care. Fifth, there must be adequate community support available. The most important factor in all of the above is number four. As one doctor puts it, "What you really need is some people who are committed."

9. The major obstacle which stands in the way of bringing chronically ill children home is lack of funding. Either no funding exists, or ironically, there is a bias in government and private health insurance programs in favor of institutionalization. What this means is that families face a Hobson's choice. They can either leave the child in the hospital where care will be reimbursed, or bring the child home where there is little or no reimbursement available.

10. There are several programs which purport to provide financial assistance for chronically ill children, the most significant being Medicare, Medicaid, Crippled Children's Services, and CHAMPUS. Significant obstacles prevent most children from qualifying for any of these programs, and even for those who successfully navigate the maze, there is little money available for home care. The Medicare program, for example, is limited to the elderly and the disabled. After the child has been disabled in Medicare's terms for more than two years, the child might qualify for Medicare benefits. Even so, only three percent of Medicare's payments go for home care, and a tiny fraction of that is paid for pediatric home care. The basic problem is that Medicare covers only very limited kinds of home care and is focused on acute illness. It does not provide payment for chronic conditions other than end-stage renal disease which exist over the long-term.

    Medicaid is a program which is only available to the poor. Income and assets limits of this federal-state grant-in-aid program are set by the states at comparatively low levels. In order to qualify, most families have to "spend down" their assets, and sell off their home and possessions, using this money to provide care. Medicaid might then provide coverage if their income level isn't much over $5,000 a year. One way around this roadblock is the home and

community-based waiver, in which the normal deeming requirements are set aside. This is not a solution to the funding problem because it allows a relative handful of children to obtain coverage on an "exceptions basis." Overall, however, Medicaid's home care benefit is only about one percent of the entire program. It is not really even a national program since over sixty percent of Medicaid's home care funds are expended in one state, New York. Moreover, most of the funds are spent on older Americans. No one has any precise figures, but pediatric home care probably accounts for only a fraction of the limited $750 million in Medicaid home health dollars.

The CHAMPUS program provides health care benefits to members of the armed services and their dependents. The program provides some payment for the problems of chronically ill children as long as they are hospitalized. However, there is a monthly limit of $1,000 for any child cared for at home.

11. Most major medical plans sold by commercial insurers contain a bias towards institutionalization and provide inadequate protection for technology dependent children. It is not unusual for some of these special children to spend up to the lifetime limit of their insurance policies in the first year of their lives if they are hospitalized continuously. Often this means that these children will no longer be covered by any insurance; they will be disqualified because of their so-called "pre-existing conditions." Even when there is coverage under the policy, it is often difficult to collect. One parent said, "It is like banging your head against the wall." To the extent that insurance provides coverage, the price for that coverage is to retain the child in the hospital. Coverage for home care, even though it is a fraction of the cost of comparable care in a hospital, is generally not accepted. One major exception: Aetna Life and Casualty provides excellent coverage under a program they call Individual Case Management.

12. Thousands of children live in hospitals and institutions not because they need to be there, but because that is the only place where reimbursement is available for their care. Prolonged hospital stays pose significant problems, including the following: (1) development of the children is hindered so that they are, in the opinion of experts, "years behind their peers;" (2) bonding between parents and their child is inhibited when the child is the responsibility of the hospital; (3) having a chronically ill child in the hospital produces tremendous stress, more so than having the child at home, and can have the effect of pushing the family apart; (4) a hospital environment is a regulated, regimented existence, depriving the child of his or her freedom and of the opportunity to enjoy the highest quality of life; (5) in some instances, a hospital environment can be dangerous. The risks of infection for ventilator-dependent children are much greater in the hospital than they are at home.

13. Home care has significant advantages for most chronically ill children. Among these advantages, according to experts, are the following: (1) the quality of the care rendered by trained parents augmented by professional nurses is just as good, if not better, than what is available in the hospital; (2) the home offers a more positive environment, promoting both improvements in the child's mental attitude and in his or her medical condition; (3) having the chronically ill child at home can reduce the significant levels of stress which parents face in these circumstances; (4) home care aids in the child's development. One physician said, "They just blossom;" (5) home care is generally less expensive, often costing only ten to twenty-five percent of comparable care in a hospital; (6) home care offers children freedom and preserves their right to treatment in the least restrictive environment; (7) home care helps keep families together; (8) home care helps provide children with the highest quality of life.

14. Parents need training and support if they are to successfully take on the care of their chronically ill or severely disabled children at home. Some children have to be watched twenty-four hours a day for fear that they will not continue breathing. Without help which enables the parents to get some sleep, the care of the child for more than a day or so would be impossible. If properly trained, parents can assume many of the duties which were performed for the child in the hospital, but not all of them. Some procedures must be performed only by licensed nurses in conformity with state law and the best interests of the child.

15. Chronically ill children cared for in home care programs need continuing follow-up care by physicians on a regular basis, and under some circumstances they need to be readmitted to the hospital. Unfortunately, some families find that once they bring their children home, it is hard to get them back into the hospital when that is what is needed. This appears to be a function of third party reimbursement, which is both limited and inflexible, as noted above.

16. Service coordination, or case management, is a very important part of a successful pediatric home care program. What this means is that someone must accept responsibility for coordinating all the care and services that the child needs. One parent described caring for one of these youngsters as "kind of a three ring circus." Another said that it was like trying to replicate all divisions of the hospital in your home. Parents need the assistance of a social worker or other health professional who can help them get the supplies and services that are needed by the child. The help is needed in part because the current system is so fragmented and disorganized that it takes skilled hands and experience to navigate through the maze to reach the goal of quality home care.

17. Even after parents have been successful in bringing their children home, they live with dangerously high levels of stress. The degree of stress they face increases directly with the severity of the child's condition and inversely with the amount of support that is available to them. Many families live on a daily basis with the fear that their child may stop breathing and die unless they are able to resuscitate him or her. Parents live always on the alert, their lives revolving around the child, a fact which produces a high degree of stress.

18. There is no scientific study, but the best evidence suggests that having a chronically ill child generally brings a husband and wife closer together. The variable seems to be the solidarity of the marriage in the first place. Stronger marriages seem to benefit, while the pressure seems to shatter weaker ones. The above opinion is complicated by the fact that fifty percent of all American marriages end in divorce, and it is really impossible to sort out all of the causes for the dissolution, let alone to point to one factor as the proximate cause of the termination.

19. Having a chronically ill or severely disabled child in the family can have profound effects on other siblings. Older children normally feel rejection and suffer a sense of loss when a new baby is brought into the family. This sense of rejection is accelerated when the child is chronically ill and totally consumes the attention of the parents. The effects on other children are highly variable, but it is not unusual to have them withdraw, become depressed, fake illnesses of their own, or indulge in socially unacceptable behavior in order to get attention. In other instances, the older children understand and tolerate the situation, often pitching in to help the parents with the care of the new infant. In the home care setting, there is no question but that the chronically ill child benefits from having the company, the love, and support of his or her siblings.

20. Having a chronically ill child puts a severe strain on friendships. The consensus among family members is that having an ill child over a long term is damaging to outside relationships. Parents said that they simply did not have the time and the energy which was needed to sustain them. "You can't really share something this intense and complicated," said one family member. Families of technology dependent children make new friends in networking with others who share their situation. Such support groups made up of parents of chronically ill children are extremely important.

21. Families are in agreement that despite all the pressures, having and caring for one of these special and fragile children is the highlight of their lives. Asked what was their happiest moments, parents were unanimous: bringing the child out of the hospital to be cared for at home.

22. The most difficult moments in the lives of these families generally involve a health crisis where the child hovers on the edge of death. Equally difficult moments are trying to find funding for home care and wrestling with insurance companies who should pay under the terms of their contract, but who do not.

23. Once a child has been cared for by his family in the home setting, rehospitalization of the child can have highly negative effects. The children may regress in their development, becoming withdrawn and depressed. Speaking of one such child as an illustration, one physician said: "It would be disasterous. It would create a depressed child who in fact may even withdraw from the world."

24. Families and medical professionals alike are in strong agreement on the need for respite care to maintain the success of any pediatric home care program. Families need a break from the pressure. Respite can be in the form of having someone else watch the child during eight hours of the night; otherwise, one parent will have to stay up with the child. Parents need some time to themselves, an opportunity to run errands, to take care of their own needs, or just to rest. A short respite will allow most families the chance to gather the strength they need to continue to provide safe care for their youngster.

25. Children who are dependent upon modern technology need education just as much as other children. In fact, the need may be even greater depending on how much of his or her formative years are spent in the hospital. Parents must be taught how to help their children, and when the children reach school age, provision must be made by public schools for their education.

26. Health care professionals who deal with chronically ill children need special training. Schools of medicine and nursing should place greater emphasis on the special needs of technology dependent children and the possibilities for home care. The simple fact is that many nurses who were educated ten, fifteen, or even five years ago do not have an adequate understanding of the existing technology. In most instances, the quality of care has been good, but in some instances it has not been acceptable.

27. One of the primary conclusions of this report relates to the need to educate the American public. Relatively few people understand the extent of the technological revolution. Only about forty percent of the American public knows about home care as an alternative to keeping chronically ill or severely disabled children in the hospital. There is a need to inform affected families in particular, since most of them have nowhere to turn when their child is born with long-term health care problems.

28. There is a strong need for pediatric hospice programs. Hospice involves a coordinated program of palliative and supportive services to the person and his or her family. Unfortunately, there are few entities which provide hospice services for children, and there is no reimbursement for it under public programs. Given the fact that the number of these fragile youngsters will continue to increase over time and the fact that many of them will die, a national pediatric hospice program of some sort would be an excellent idea.

29. Pediatric home care is significantly more cost effective than comparable hospital care. The main reasons why children should be cared for at home are: (a) it is better for the child; (b) it is better for the family; and (c) it keeps families together. The fact that home care is more cost effective than care in a hospital, sometimes by a margin of ten to one, is an added bonus. However, the fact, that pediatric home care is more costeffective tends to point up the failure in public policy. Public policy has not kept pace with the changes in technology.

30. Pediatric home care benefits very dramatically from state to state. As a result, parents may be forced to uproot the family and move to a different jurisdiction in order to secure adequate funding for their chronically ill or severely disabled child.

31. Modern technology, which has saved the lives of thousands of children who previously would have died, may itself provide the answer to many of the dilemmas posed by the survival of these children. The technology has been miniaturized and made portable so that it can be available at home and, indeed, can follow along with the child wherever he or she might choose to go. Much of this technology was developed as a spinoff of the U.S. space program, where it was necessary to be able to monitor the health and vital signs of astronauts thousands of miles from the earth. This technology in the hands of competent medical and nursing professionals and adequately trained family members promises not only to lengthen, but also to enrich the quality of life for millions of American children in the years to come. All that is necessary is for third party payors, including the government, to agree to pay for its use in the home as well as in the hospital.

32. When asked what advice they would have for other parents in similar circumstances, the families of technology dependent children were unanimous. Sandy Reckeweg spoke for all when she said:

> "Fight for home care 100 percent because it is very well worth the effort; it is worth every ounce of energy that you put into these kids, to see them grow and develop to their fullest potential."

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March 23, 1987

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The Foundation for Hospice and Homecare was established to advance the interests of those Americans former Vice President Hubert H. Humphrey described as being on the "fringes of life" - the young who are greeted with enormous health problems at the dawn of life, the very old who face compounding health problems in the twilight of life and the handicapped who are hidden in life's shadows.

In 1985, in response to this charge, the Foundation's policy arm - Caring Institute - established pediatric research as one of its top priorities. Since that time Foundation and Caring Institute staff have searched the available literature for information concerning the problems faced by chronically ill children. They have investigated the issue in ten states and conducted dozens of interviews of parents and health professionals.

As a result of this investigation, we have prepared a soon to be released documentary, "Suffer Not the Little Children", which is narrated by Ms. Susan Sullivan, and the excellent report that follows - "The Crisis of Chronically Ill Children in America: Triumph of Technology - Failure of Public Policy."

It is our conclusion that thousands of children are needlessly institutionalized and deprived of their fundamental rights. That this is allowed to occur is injustice enough. That it occurs simply because we have not focused on this problem and the compelling arguments for bringing these children home is a startling indictment of our society.

We release this report with the hope that it will contribute to the correction of this intolerable situation. In so doing, I would like to commend all of those on the Foundation and Caring Institute staff who contributed to this project. Tom Cline deserves special recognition for his tireless efforts as does Nancy Pinkard.

Frank E. Moss
Chairman, Board of Trustees

THE CRISIS OF CHRONICALLY ILL CHILDREN IN AMERICA:
TRIUMPH OF TECHNOLOGY -
FAILURE OF PUBLIC POLICY

A Report by the Caring Institute
of the
Foundation for Hospice and Homecare

Washington, D.C.
March 23, 1987

TABLE OF CONTENTS

	Title	Page
	Executive Summary	i
I.	Introduction	1
II.	The Numbers: Background on the Fragile Minority	3
III.	Advances in Medical Technology	9
IV.	Case Histories of Chronically Ill Children	14
V.	The Need for Pediatric Home Care: An Exposition of Issues	34
VI.	The Funding Roadblock	65
VII.	Arguments in Favor of Home Care, Including Cost Effectiveness	78
VIII.	Service Components of Pediatric Home Care	89
IX.	Summary and Conclusions	95
X.	Recommendations	101

EXECUTIVE SUMMARY

This report examines a blight on the American conscience--the clear deprivation of the civil rights of the most vulnerable members of society--chronically ill children.

The report examines the unlikely, but accurate fact that thousands of American children are held as virtual prisoners in institutions. These fragile children have been deprived of their freedom and are being robbed of an opportunity to grow and develop to the full extent of their God-given abilities.

Day after day these children live a regimented, regulated existence, confined to rooms without windows, isolated from their parents, their brothers and sisters, and all of society.

They spend months, if not years, under hot lights in tiny cribs, never seeing the clouds, the trees, or other wonders of nature. They have never had a chance to hear a bird sing or to hear the ocean roar. They have never smelled bread baking or flowers sprouting from the ground after a spring rain. They do not know what it means to play, and for the most part, they have never learned what happiness means.

The worst offenders are kept in solitary confinement, in total isolation except for those who guard over them. Visitors are carefully restricted to certain hours. Only one parent is allowed in at a time; sometimes, brothers and sisters are barred from visiting altogether.

The crime these youngsters have committed is to be born less than perfect in a society which prizes perfection. The length of their confinement can be for months or years, or even for life.

As with other similar confinements, rationalizations are offered which have little to do with fact. It is asserted, for example, that placing them in this restrictive setting is for their own good or that even if this setting is not in the child's best interest, society simply has no alternative. Others would argue that confinement is in the best interests of society in general.

The plain and simple fact, and the major conclusion of this report, is that these youngsters could and should be home with their parents. The fact that they are not represents a colossal failure in public policy. It is that failure which is examined in this report.

The only bright spot in this unhappy scenario is that the problem is a recent one. It has been manifested in the United States only in the past five to ten years. But even the most conservative estimates indicate that the problem will increase by geometric progressions in the years to come. It is vital, therefore, that the nation come to grips with the problem and immediately fashion a policy which restores to these infant Americans their full complement of Constitutional rights. The failure to do so will not only deprive the children, but impoverish the nation.

This study and this report are the result of two years' work. In addition to traditional research, dozens of families and caregivers were interviewed. Physicians, nurses, aides, social workers, discharge planners, therapists and other health care professionals were sought out for their opinions. The research took place in ten states which are broadly representative and which collectively account for approximately fifty percent of all national expenditures on health care.

The states where interviews were conducted were: Arizona, California, Connecticut, the District of Columbia, Illinois, Maryland, Michigan, New York, Pennsylvania, and Virginia.

Some of these interviews were conducted on videotape. The result of this activity is the documentary film, 'Suffer Not The Little Children,' narrated by Ms. Susan Sullivan. The interviews were rich in information and experience. Chapter II of this report carries excerpts of many of the interviews organized around various issues.

Chapter II attempts to answer the questions of who these children are and what their special problems are. The report concludes that ten to fifteen percent of all children, or roughly ten million youngsters, have a chronic illness. About two million of this number are severely impaired.

Many of these children are born premature. As such, their internal organs often are not fully developed. In other cases, the youngsters were carried full term but suffer from congenital disabilities.

Many of these children fall into eleven categories, or what have been called "marker" diseases. They are: leukemia, cystic fibrosis, congenital heart disease, spina bifida, asthma, hemophilia, chronic kidney disease, juvenile diabetes, muscular dystrophy, cleft palate, and sickle cell anemia. A small but rapidly growing number are children who are victims of AIDS.

To the numbers mentioned above must be added several million accident victims. Accidents are the highest cause of death of American children.

The numbers above are significant for many reasons. It is significant to note that this small minority of the nation's children currently account for about forty percent of all pediatric in-patient days in hospitals in the United States.

Many of these youngsters live in pediatric intensive care units of the nation's hospitals, and a lesser number are in nursing homes. They are sometimes called "million dollar babies" because the cost of their care may exceed $1 million dollars a year.

The children are also known as "technology dependent," a reference to the fact that they owe their very lives to modern technology and continue to be dependent upon it to some extent. It is the evolution and refinement of such technology which make it possible for these special children to be cared for at home.

Chapter III of this report describes some of the technology which was at first only available in the hospital. This new equipment has now been made smaller, more portable and even adapted for battery power. Examples include not only new equipment but new treatment modalities.

For example, most people would be surprised to know that intravenous chemotherapy, the infusion of cancer fighting drugs into the blood stream, is now routinely done at home. Studies indicate that the procedure is not only less stressful for the patient, but also produces better therapeutic results and minimizes side effects.

Another example is Total Parenteral Nutrition (TPN), which involves intravenous feeding of a child who otherwise cannot eat. Kidney patients receive dialysis at home. Heart patients are watched by means of cardiac monitors and tested with portable electrocardiogram units.

Children who are in danger of dying because of Sudden Infant Death Syndrome (SIDS) can now be guarded by means of machines called apnea monitors. The machines trigger an alarm if the child's breathing slows significantly and/or if the child goes into respiratory arrest.

Most impressive of all, children who depend on an artificial device called a ventilator to do their breathing for them can, and are, being sent home. Some ventilators are small enough that they can be placed on the back of a wheelchair, following the child wherever he or she might want to go.

Chapter III of this report includes a dozen case histories. Family members talk about their children in their own words. The reader will meet a number of charming youngsters including the following:

- Robert, a four-year-old who lives in the District of Columbia, has a rare muscle disease. Robert is making progress intellectually, but his muscles do not have strength. He cannot sit by himself, feed himself, or breathe without assistance from a ventilator.

- Five-year-old Jeffrey is one of a handful of children in the world known to have a strange disease called Ondine's Curse. For some mysterious reason, when Jeff sleeps, his brain forgets to tell his body to breathe. His life is sustained by mechanical breathing and monitoring aids.

- Alex, also five, has Tay-Sachs disease. When he was two, his development began to reverse. He has regressed to the point where he can no longer eat, drink, or move on his own.

- Stephen is in his early twenties. He has Duchenne's muscular dystrophy. He is in a wheelchair and is ventilator dependent. He lives at home, but requires twenty-hour nursing care, without which he would have to be institutionalized.

- Katherine is 17. She has a genetic abnormality called Trisomy 18 which has resulted in multiple severe impairments. She suffers from heart, kidney, and intestinal ailments, and is prone to seizures. She cannot hear or speak or turn over in her bed. She is at home with her family, but requires constant skilled nursing assessment for her deteriorating heart condition.

Chapter V summarizes the opinions of parents and medical experts on a wide variety of issues. These responses form part of the basis for the following conclusions:

- The primary emotions of parents whose child suffers from birth defects or anomalies are fear and frustration. The words most commonly used by parents to describe their reaction were: "We were terrified."

- Most families want to have their children at home with them. Contrary to mythology, most families do not abandon their children if they are born with anomalies. They accept them and want to have them at home as part of the family unit.

- Physicians are in agreement that it is possible to manage the care of most children at home--even complex cases involving multiple disabilities.

- Physicians were in general agreement as to the criteria which must be met before a child can be discharged from an institution into a home care setting. First, the child must be medically stable. Second, the transfer to the home must offer the child an improved quality of life. Third, the transfer to the home setting must be an acceptable risk. The risks must be small enough to be offset by the advantages of having the child at home. Fourth, the family must be willing and able to take on most of the child's care. Fifth, there must be adequate community support available. The most important factor in all of the above is number four.

Parents need help, training, and support if they are going to successfully care for their chronically ill infants at home. Respite care is not a luxury, but a necessity. Someone must give the parents some relief from the heavy burden of watching over the child twenty-four hours a day. While parents can be trained to perform many procedures, others must be performed only by licensed nurses in conformity with state laws and the best interests of the child.

Bringing their child home is the happiest day for most parents of chronically ill children. While it reduces the level of stress, family members continue to live with dangerously high levels of stress.

Medicare, Medicaid, Crippled Children's Services, CHAMPUS and other government programs provide very little, if any, help and have a bias in favor of institutionalization. Private health insurance is also inadequate and suffers from the same bias.

Prolonged hospital stays pose significant problems for children. Specifically, their development is stunted, bonding between them and their parents is inhibited, the child is deprived of freedom and placed in an environment which, for all its life-saving potential, is more dangerous to the child, and significant stress is produced by the very fact, that the child is in the hospital.

On the opposite side of the coin, care of the child at home by his or her parents with requisite support has overwhelming advantages. Specifically, it is better for the child and aids his or her development. It also keeps families together, reduces stress, provides the child with freedom and the opportunity to live the highest quality life, and is more costeffective.

Chapter VI reports in detail on what the parents of the chronically ill children claimed was the greatest obstacle standing in the way of their bringing their child home--lack of funding. Government and private programs are described as a patchwork quilt, a maze of exceptions, a collection of promises, describing entitlement in big print, which are effectively vitiated by exceptions spelled out in the small print.

It is this labyrinth that forces parents to quit their jobs and move from one state to another, looking in vain for some state with a more comprehensive and humane policy which will allow them to care for their child at home. It may force some families to literally give up their babies, to have them become wards of the state in order that they might receive the care that they need.

This lack of a meaningful policy causes families to make a Hobson's choice. They can either leave their baby in the hospital for months or years at a time where care will be reimbursed, or they can bring their child home, knowing there is little, if any, reimbursement available.

Chapter VII examines the question of cost effectiveness of home care for chronically ill children in some detail. The chapter also draws on two types of case studies: those of individual children and their parents, and those reported by various authoritative agencies, either as part of a demonstration project, or as based on their experiences.

The conclusion: care in the home is almost always much less expensive than comparable care in the hospital. Home care enjoys the cost benefit by margins as high as eighteen to one over hospital care. It is quite common for home care to cost only one-tenth the cost of comparable care in the hospital. Most actual experience and most studies indicate that home care costs average only about one-fourth or one-fifth of the cost of care in the hospital.

One insurance company, AETNA Life and Casualty, has seen the wisdom and advantages of home-based care and has developed what it calls its Individual Case Management (ICM) program. AETNA reported savings of $36 million in 1985 through use of the ICM program. The savings were possible in part through implementation of the parents' wishes to bring their child home from the hospital.

Chapter VIII describes the service components of pediatric home care. Service coordination, or case management, is very important to the success of any pediatric home care program. What this means is that someone must accept responsibility for coordinating all the care and services that the child needs. One parent described caring for one of these youngsters at home as "kind of a three ring circus." Another said it was like trying to replicate all the divisions of the hospital at home. Parents need the assistance of a social worker or other health care professional who can help them obtain supplies as they are needed by the child.

Parents need help in obtaining services in part because the current system is so disorganized, fragmented and incomplete that it takes skilled and experienced hands to develop a quality home care program and to have the components of care paid for by some entity.

This chapter also talks about the importance of educating caregivers. Doctors and nurses and other medical professionals must be trained as to the special needs of chronically ill children. They need to be educated as to the availability and potential of the home care alternative to institutionalization. Considering its importance in terms of its effect on the child's development, the home far and away provides the setting of choice for care whenever possible.

Finally, the report describes some possible dangers. It suggests that policymakers take care to ensure that children are only sent home when and if adequate medical, nursing, and social support services are available. It would be the ultimate disservice to begin indiscriminate dumping of children from institutions into the home without committing requisite resources to ensure that they are well cared for. Moreover, care must be taken to make it possible for the child to return to the hospital for treatment whenever necessary. Of equal importance is the need to ensure that home care professionals are adequately trained so that they provide the highest possible quality of care.

Chapter IX of this report provides a summary and conclusions. Therein, it is asserted that the United States stands at a point of crisis with respect to millions of chronically ill children. Most of these children could and should be at home. It is better for them, better for their families, and better for the nation. With help, many of these children will outgrow their ailments. With assistance, most of them will develop to the full extent of their abilities and have a reasonable opportunity to lead meaningful lives

and to contribute to society. Whether they have this opportunity and the full panoply of rights which is theirs under the U.S. Constitution remains to be decided. It is the conclusion of this report that the Constitution and the Bill of Rights were meant to be inclusive. It did not specifically exclude chronically ill children from its protections. It is more than appropriate that the immediate injustice, the blight on the American conscience, be removed at once.

Chapter X offers recommendations for a restructuring of our national health care policy to address both the immediate and the long-term care needs of the pediatric population. The principal recommendations are:

(1) Expand Crippled Children's Services to provide a comprehensive home care alternative which includes federally-mandated eligibility and coverage criteria and respite;

(2) Revise the CHAMPUS program to make comprehensive home care available to the children of armed forces personnel; and

(3) Create and fund a program of pediatric hospice care.

Others recommendations in Chapter X are:

(1) Revise the Medicare program to ensure home care availability for chronically ill individuals over the age of eighteen;

(2) Provide incentives for, and encourage private insurers to, remove the institutional bias in existing health insurance policies by making home care available to chronically ill or severely disabled children;

(3) Increase education and training of medical personnel to handle the problems of our new technology and the resultant population of medically fragile children;

(4) Increase public awareness of the availability of the home care alternative to institutionalization;

(5) Continue and expand research into the causes and potential cures of the eleven marker diseases of chronically ill children; and

(6) Establish educational opportunities programs for the burgeoning class of technology dependent children.

I. INTRODUCTION

President Reagan declared in 1983 that "[m]ore than anything else, we seek the blessing of good health for our children. We hope for the sound minds in sound bodies that lead to lives of strength and achievement." Nevertheless, each year some 140,000 babies are born in the United States who suffer from one or more partially disabling conditions, and nationwide, up to two million children are deemed to have severe chronic illnesses. Thousands of others are the victims of serious, crippling accidents in their youth or adolescence, and another eight million have some form of chronic health impairment.

A generation ago, the prognosis for some of these children would not have been good. But advances in medical technology in recent years have not only increased the likelihood of survival among this group, they have also improved their chances to lead useful and productive lives. The degree to which these "technology dependent" or other chronically ill or disabled children are able to survive and contribute depends in large part on how this society chooses to allocate its health care resources.

A substantial number of the children in question require extended institutional care early in life. However, technology has made it medically possible for ever-increasing numbers of them to leave the impersonal confines of hospitals and other acute care facilities and resume their lives at home. This nation places a premium on the family and on the contribution of that unit to society. Ironically, though, it has not marshalled its vast resources in full degree to return as many children as possible to their homes for care. To the contrary, our inability or unwillingness to conform public policy to the realities of medical science has resulted in a cruel perversion of that policy. While Medicaid and private insurance will pay for continued care in the hospital for handicapped children, these benefits are often withdrawn should the parents bring their children home: this despite the fact that the cost of home care is often only a fraction of the cost of hospital care. Parents are literally forced to keep their children confined in hospitals because the alternative, though cheaper, is unaffordable.

This report seeks to address the dominant issues surrounding pediatric home care. It focuses on the major impediments to bringing the chronically ill or severely disabled child home for care and for incorporation into the structure of the family and the community. It discusses solutions, as proposed by parents, doctors, and others, to these obstacles. Above all, the report emphasizes the enormous advantages in human, as well as financial, terms to be derived from a sensible national policy in support of pediatric home care.

The Foundation for Hospice and Homecare has tried to present these problems and proposals from the most important perspective of all: that of the children and their families. For while the preliminary data indicate significant cost savings associated with home, versus institutional care, the greatest benefit of all is in human terms. Returning the child to his or her home when possible promotes the integrity and well-being of the family unit. It fulfills the fundamental right of any child to receive the love and affection of parents and siblings. It is also likely that the child's recuperative and restorative functions are increased in the home environment, surrounded by that love and support. Finally, the increase in the child's long-term productive capacity attributable to nurturing in the home environment seems clear and unassailable.

Against this array of benefits, there is little to argue against the establishment of a national public policy supporting pediatric home care. That is not to say that such a policy is risk-free. It is imperative that guidelines be established within the medical community for determining when a child is capable of being cared for at home. It is

equally important that ethical guidelines be formulated for the presentation to parents of the viable options for care and of the prognosis, so far as medically determinable, under these options. Finally, appropriate service components, such as psychosocial support programs for families of pediatric patients, must be established to assist with the non-medical side of home care.

The home, the family, and the medical community are truly untapped resources in delivering health care to chronically ill and severely disabled children. Despite some risks, the step toward increased pediatric home care is one worth taking. If this report puts the advantages of that step into clearer focus, then its purpose will have been served.

II. THE NUMBERS: BACKGROUND ON THE FRAGILE MINORITY

Our mental image of our children is a positive one. We hear their laughter. We see strong and healthy bodies at play and alert, inquiring young minds mastering the elements of reading, writing, and arithmetic. The environment in which we see them is also positive: a comfortable, happy home where they are surrounded by loving parents and siblings. These are the ideal perceptions.

For a substantial group of American children, these perceptions are nothing more than an ideal. Reality for this segment of our population consists of physical or mental impairment, pain, and dependence on others and on machines for assistance in the daily affairs of life. For these children, the home is all too often a small oasis in a desert of institutional care. In the words of the Surgeon General of the United States, theirs are "tiny, vulnerable, ruptured lives."

Most of us have little or no contact with these handicapped children, yet their numbers are significant. According to Vanderbilt University Institute for Public Policy Studies, there are perhaps one to two million children in this nation who suffer from severe chronic illnesses. Another ten to twelve million children may be afflicted with some degree of chronic health impairment which interferes with daily functioning. Accident victims add to this number. Depending on the degree of severity, then, anywhere from one to twenty percent of the country's children exist outside the ideal.

They are a fragile minority. They are the victims of public ignorance and misunderstanding. For this reason, a nation which prides itself on the attention it gives to its young and to the family unit has yet to focus its vast resources and creativity on the problems of the chronically ill child. Antiquated policies and an absence of impetus for change have condemned many of these children to a continued limited existence in hospitals and other acute care facilities at the very time advances in medical technology might release them to happier and more productive lives in their own homes. They are captives not out of necessity but out of lethargy. Their plight demands that we re-evaluate our national health policy.

To whom are we referring when we speak of the class of chronically ill children? Their health disorders take many forms. However, we can categorize them by reference to the most frequent, or "marker," diseases which represent the many dozens of severe and rare chronic illnesses that afflict our children. Among the more prevalent chronic illnesses are the following: leukemia, cystic fibrosis, congenital heart disease, spina bifida, asthma, hemophilia, kidney disease, juvenile diabetes, muscular dystrophy, cleft palate, and sickle cell anemia. These diseases are briefly described here to provide an overview of the affected population. (NOTE: The information on these disorders is found in Hobbs and Perrin (eds.), *Issues in the Care of Children with Chronic Illness* (San Francisco, 1985).

* * * * * *

Leukemia: Cancer is the second leading cause of death among children under the age of fifteen. Each year, there are about 6,000 new cases of childhood cancer in the United States, of which approximately 1,900 are childhood leukemia. Childhood leukemia is either acute (99%) or chronic (1%). The former is characterized by the replacement of bone marrow with undifferentiated or immature cells known as blasts, while the latter is the malignant spread of differentiated or mature cells. In both cases, the cancerous cells can spread to other parts of the child's body.

The mortality figures for childhood leukemia no longer bear the one-to-one correlation with incidence rates that they did in years past. Dr. Perrin has estimated that 50% of children with that diagnosis will "have a long-term, apparent cure." Treatments include radiation therapy and IV chemotherapy. In some instances, the latter is accomplished at home or as an outpatient procedure. Therapy is costly, in addition to which there are out-of-pocket expenses the child's family may incur for travel to and from treatment facilities, for lodging, and for time lost from work during therapy sessions.

Cystic fibrosis: Cystic fibrosis (CF) is a congenital disorder which occurs in between 1,500 and 2,000 cases in the United States each year. The Cystic Fibrosis Foundation has 12,000 registered cases in 1980, but it is suspected that the actual number is two to four times greater.

CF results in abnormally viscous secretions of the exocrine glands and also inhibits normal clearing of bacterial and fungal pathogens from respiratory secretions. Most CF patients live into their teens or early twenties before succumbing to pulmonary disease.

CF patients rely on respiratory treatments for the very air they breathe. They must generally be hospitalized several times a year for respiratory complaints; a survey done on a limited number of patients in 1979 found average hospitalization costs for these individuals of $11,745. Prescription and non-prescription medications, out-patient treatments, equipment for lung care, physical therapy, and other out-of-pocket expenses place additional burdens on the family of a child with cystic fibrosis. Some assistance may be available from government programs such as Medicare, Medicaid, or Crippled Children's Services, but the scope and amount of assistance vary widely.

Congenital heart disease: Congenital heart disease accounts for most instances of cardiac illness in children. It encompasses any abnormally formed heart.

With the miniaturization of diagnostic and surgical techniques we have witnessed over the last twenty-five years, greater numbers of children with cardiac conditions are surviving. Cost of care, again, is exceedingly high and well beyond the average family's ability to pay without assistance. A 1975 study estimated first-year hospital costs for surviving children at between $7,200 and $16,700. Dr. Donald Fyler of Children's Hospital in Boston predicted that 1985 figures would be four times greater.

Spina bifida: Affecting two of every one thousand infants born in the United States each year, spina bifida is the second most common birth defect after Down's syndrome. It embraces a variety of similar disorders that have in common a failure of the bony spine to develop properly. Approximately 95% of children recognized as having spina bifida exhibit a protrusion of the spinal cord and its covering membrane through the bony spine.

The spina bifida child may suffer from related abnormalities, including hydrocephalus, curvature of the spine, and distortions of the chest. Paraplegia may also be present. Modern neurosurgery and antibiotics have resulted in significant increases in survival rate. With treatment, the prognosis for survival and even independence of the spina bifida patient is good. However, the condition is associated with chronic disability, and survivors face lifelong medical care and repeated operations. Crippled Children's Services and Medicaid dollars are available in some states to help defray the costs of medical treatments.

Asthma: The U. S. Public Health Service estimated in 1979 that five percent of all children under the age of fifteen have or have had symptomatic asthma. Some authorities believe this to be an underestimate. Regardless of the correct figure, asthma is one of the most common of childhood diseases.

Death is a rare result, but the restrictions asthma places on certain activities can be great. It is probably the most frequent cause of school days missed among children in the under-fifteen age group. Its symptoms include dyspnea (difficult breathing), cough, wheezing, and pseudo-pneumonia. An asthma attack may be triggered by any of a wide variety of stimuli, including allergy, infection, exercise, irritants, climate, and even emotional stress.

Hemophilia: Hemophilia is a life-long, inherited disease characterized by a deficiency of a protein essential to proper clotting of the blood. It occurs only in males.

The disease can take several forms; collectively, it was estimated that there were approximately 18,000 patients in the United States in 1980. Because the recessive gene which carries hemophilia is no longer lethal and because more patients are reproducing, it appears that the prevalence of this disease is increasing.

Severe hemophilia is manifested in frequent, spontaneous, painful bleeding. Bleeding usually occurs into joints such as ankles, knees, hips, and elbows. Unless it is halted, it results in joint destruction and crippling. Prior to the development of replacement therapy, most severe hemophiliacs were significantly crippled by age twelve and wheelchair-bound as adults. Death usually occurred at an early age, often as a result of intracranial hemorrhaging.

Less severe forms of hemophilia may also be present. Life expectancy for the hemophiliac population has been prolonged markedly, but the chronic nature of this disorder means constant financial and psychological demands on patients and families. Cost of treatment is high. Again, Medicaid and Crippled Children's Services help meet some of the expenses for some patients in some states, but coverage is far from complete. As with other chronic disease, there is some evidence that extending home care programs to more patients has led to a decrease in costs.

Kidney disease: Chronic kidney disease is defined as an irreversible abnormality of kidney function. This abnormality may affect any of the kidney's normal activities -- controlling salt and water, aiding in the metabolism of various hormones, and excreting the waste products of protein metabolism -- but failure to perform the excretory function can lead to damage to other organs or death.

The disease is relatively rare, and advances in dialysis and organ transplants make it survivable in most instances. Nevertheless, children with end-stage renal disease may still be victimized by bone disease and growth retardation. Such children are entitled to reimbursement for the costs of care under Medicare, yet serious gaps in services remain. In this instance, as in others, it appears that treatment at home, where appropriate, is significantly less expensive than treatment in hospitals or other care centers.

Juvenile diabetes: Diabetes, a disease resulting from a deficiency of the hormone insulin, is fairly common, with estimates of prevalence in the American population ranging from two to four percent. The per-year incidence of insulin-dependent diabetes mellitus (the form characteristically seen in children) is approximately fifteen per hundred thousand normal children and adolescents under twenty years old. Insulin dependent patients are especially susceptible to small blood vessel disease, which can lead to damage to eyes, peripheral nerves, or kidneys. Such

patients also experience increased mortality from accelerated hardening of the arteries.

Financial assistance may be available to some patients from Supplemental Security Income (SSI), Medicaid, Crippled Children's Service, state and federal renal disease programs, or state diabetes programs. Private insurance is difficult for the diabetic to obtain, and when available, is often prohibitively expensive.

Muscular dystrophy: Muscular dystrophy may take one of several forms. All are progressive, inherited disorders of the muscle cell. Estimates on incidence of muscular dystrophy vary from thirteen to thirty-three per hundred thousand live male births. Within the population as a whole, the prevalence is estimated at about three per hundred thousand.

Duchenne's muscular dystrophy is the most common of these disorders seen in childhood. Its manifestations begin as early as three years of age, and the afflicted child experiences a steady degeneration of muscle control from that point. The disease causes a loss of function in the upper extremities, and death usually occurs at about age twenty either from damage to the heart muscle or, more commonly, from respiratory failure. Full-time ventilator dependence can add to this life expectancy, but no medications exist either to cure or control the progress of Duchenne's.

Other forms of dystrophy are not as common. Like Duchenne's, they are incurable, but life expectancy may be somewhat longer. The result is that handicapped children, who may have received some assistance from Crippled Children's Services, often become handicapped adults with no financial assistance and with no organized systems of support.

Cleft palate: Cleft lip and/or palate is one of the more common birth defects, with an incidence ranging beteen 0.6 and 1.3 per thousand births. Clefts can result in significant physiological disturbances, affecting respiration, speech, hearing, chewing-swallowing, and the infantile and sensory/exploratory behavioral systems. In addition, the cleft's location in the center of the infant's growing face can impact upon facial skeletal, dental, muscular, and soft tissue growth. Numerous surgical and dental procedures may be required to minimize distortions; they are time-consuming and expensive, but the prognosis for children with this defect is good if they have adequate psychosocial support.

Sickle cell anemia: Sickle cell anemia is a hereditary disease which occurs predominantly among blacks in the United States. It has an incidence of approximately 0.2 percent of live births.

The sickle-shaped blood cells which characterize the condition have two disease producing properties. They are very fragile, resulting in anemia because of the body's inability to generate enough blood cells to keep pace with their rate of destruction. Also, their rigidity and abnormal shape make these cells more difficult to propel through the capillaries and cause temporary or permanent organ dysfunction and structural damage as a result of obstructed blood flow.

Pain is the most common symptom experienced by a child with sickle cell anemia. Life expectancy is reduced by the disease, but it is not well known to what extent. Therefore, long-term medical care and related costs, financial and emotional, result.

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These illnesses obviously share certain characteristics. They place emotional and psychological strain on child and family that can reach unbearable proportions unless counseling and support systems are available. Respite care, homemaker-home health aide services, and other programs to assist the family members are also vital.

In addition, the conditions are often costly to treat. The price for direct medical treatment, including hospitalization, is high, and long-term care is often financially burdensome, too. There are expenses for drugs, blood and blood products, insulin, syringes, orthopedic devices, oxygen, hearing aids, glasses, special schooling, and professional nursing care, to name only a few. Because most of these diseases require care over an extended time period, the costs continue to mount, draining the resources even of a family that thought itself financially secure. In fact, the costs may be so great that the family is driven into bankruptcy as insurance becomes impossible to obtain and as employment opportunities for parents and family members are severely curtailed.

A few years ago, many of these children would have been dependent on institutional care for their survival; indeed, many would not have been expected to survive beyond infancy. However, advances in our medical knowledge and capabilities have made it possible for these children to leave the confines of the hospital and to live well into adulthood. The great tragedy is that the country's response has not kept pace with these medical advances. Formal resources for the daily out-of-hospital care of the chronically ill child are totally inadequate. The medical community itself is largely unprepared to transfer the care of the child back to the home and family. The child's parents, too, are often unaware of the extent to which that care can be accomplished at home.

In testimony before the United States Senate Committee on Labor and Human Resources, Dr. Perrin provided two compelling arguments for the home care alternative:

1. Care at home by family members is healthier for both the children and their families. Children develop more soundly, socially and psychologically, when they can participate in family, community, and school life.

2. Support for care at home can be cost-effective. The largest financial costs of the very expensive care of children with severe chronic illnesses are incurred by hospitalizations. To the extent that family care can be substituted for hospital care, costs are reduced.

The latter argument -- the "bottom line" analysis -- is important. With escalating health care expenditures in both the public and private sectors, this nation must examine any feasible cost-saving measure which does not sacrifice quality care. As will be discussed later in this report, the weight of the evidence indicates that quality care at home is significantly less expensive than comparable care in a hospital or other institutional setting. However, as Dr. Arthur Kohrman, Director of La Rabida Children's Hospital and Research Center in Chicago, has noted,

> [W]e must never allow these programs to be driven by cost or potential cost savings alone. That home care is, in fact, sometimes less costly than hospital care is fortunate; however, the major reason for children being at home is because it is a better place to be for growth and development and for the wholeness of their families.

The mother of a chronically ill child agreed when she said:

We can certainly provide Katherine with care at home for less than what a hospital or skilled nursing facility would cost, but that is really not the point. Katherine belongs at home. That is not a dollars and cents issue. It is a very human issue, and a simple fact.

So, the question must be asked: why aren't more children, who could be at home, at home? Financial resources, or the lack of them, are a major reason. The United States has not formulated a comprehensive program for acute and long-term home care. Instead, we have responded piecemeal to the individual situations or to fragments of the problem without ever coming to terms with the larger issue. We have a number of federal programs which were designed to assist families wishing to care for their disabled son or chronically ill daughter in a home setting. The programs are limited in scope and eligibility and vary dramatically from state to state. The result is that the chasms between programs are vast, and most of the children who could benefit from a rational and coordinated policy instead disappear into those cracks. One example suffices to illustrate the problem. Twenty-six different agencies fund patient care in the pediatric ward of the University of Arizona Hospital, yet collectively they cover only sixty-five to seventy percent of costs.

Another byproduct of our failure to develop an overall home care plan is perhaps less obvious. Even in those instances where money is available-- either from public or private sources -- to bring a child out of the institution, there oftimes is no corresponding network of services to enable the family to cope with its new obligations. The medical profession itself is not yet sufficiently focused on the option of home care for this pediatric population. Information which the parents of a chronically ill child can use to decide between home and institutional care sometimes is not forthcoming. If it is available, it may be useless in the absence of other organized programs at the community level targeted at family preservation.

Pediatric home care patients and their families require medical services and assistance, certainly. But they require more. They need social and psychological services, access to ancillary therapies, and case management services which can constantly monitor and assess the needs of the patient and the family.

To facilitate the creation and provision of these services, we need to develop new funding strategies. We need to develop payment mechanisms for social workers and psychologists, homemaker-home health aides, respiratory therapists, and case managers. We need to increase awareness of, and emphasis on, out-patient services generally, and home care services specifically. We need to develop respite care programs and support groups.

While many of these programs should be organized on the community level, the success of a new approach to home care will turn on whether or not the federal government is willing to commit adequate resources to the task. What currently exists and what does not are the subjects of the next section of this report. As will be apparent, a fundamental change is essential.

III. ADVANCES IN MEDICAL TECHNOLOGY

This chapter explores the evolution in technology which has helped save the lives of thousands of infants who previously would have died. It briefly describes some of the advances of modern science which have been adapted to home use.

Modern science has helped reduce the risk of infant mortality. One part of this success involves better prenatal care and fetal monitoring. Dozens of tests can now be performed to measure the progress and development of the child in the womb. By extracting a small amount of amniotic fluid from the pregnant woman's womb, scientists through analysis are able to say with certainty if the child will have physical or mental handicaps at birth. It is even possible for physicians to correct some of the birth defects which are isolated in this way.

Physicians now have at their disposal a wide array of non-invasive techniques which aid in monitoring. This includes the sonogram which uses sound waves to provide images from within the womb. Also available are CT Scans, nuclear magnetic resonance (NMR) and Proton Emission or so-called PET Scans.

Once a child is born and found to suffer from medical problems, sophisticated surgery involving the lazer and the electronic microscope can correct many problems which were heretofore, incorrectable.

When the condition of these youngsters stabilizes, it is becoming increasingly possible to care for them at home. This is because new machines, technology and medical/nursing procedures have been minaturized, made portable and adapted to home usage. Following are some illustrations:

1. Apnea Monitors. Some children stop breathing for reasons no one understands. They have a high risk of death from Sudden Infant Death Syndrome (SIDS). These children need to be watched carefully, particularly when they sleep. Modern science has developed a monitor which is attached to the child, which will sound the alarm if a child's breathing slows significantly and/or if the child goes into respiratory arrest.

2. Home Phototherapy. Some infants develop jaundice, a yellow coloring of the skin caused by the deposition of a chemical, bilirubin. In most cases, the yellow coloring is the result of a normal process and will have no long-term effect. In a few cases, however, bilirubin can enter into the brain and cause severe neurological complications, including death. Such children until recently have been retained in hospitals where the goal has been to reverse the jaundice and prevent any neurological damage. Modern science has now minaturized and made available for home use a home phototherapy unit. It involves the use of special blue flourescent lights whose exposure to the skin produces a drop in serum bilirubin concentration. With proper treatment at home, the problem common to so many infants can be corrected with low risk and few side effects at home for a fraction of the cost of comparable treatment in the hospital. Thus allowing the infant to be near his/her mother during the first crucial few days of life.

3. Portable Ventilators and Compressors. Many children with lung diseases are dependent on a ventilator for their every breath. More commonly, they need the assistance of a ventilator at night while they sleep. The reasons a child might need one are many and varied, but they all relate to an obstruction of the airway

and/or an inability to breath on their own. A portable ventilator is now available to help the child breathe. It is usually accompanied by a compressor which takes on the task of helping the child exhale.

4. "Artificial Nose" and Suction Machines. Some children have difficulty breathing through their nose. In order to save their lives doctors sometimes make a small opening in the throat (tracheostomy), making in effect an artificial nose, through which the child breathes. The child does not have the benefit of the natural warming of the air that takes place when air is taken in through their nose, and may have difficulty dealing with the secretions which build up in the windpipe sometimes blocking the airway. For this reason, children with a tracheostomy require suctioning on a fairly regular basis. Portable suctioning machines have been developed. As with ventilators, there are large units available for the home, and battery powered portable units which can be used to transport the patient out of the home.

5. Portable Oxygen Units and Nebulizers. A few years ago, a child who needed oxygen therapy would have to be in the hospital. Once again, technology has been developed to the point where oxygen units of high quality are available for home use. Portable units have also been developed so that youngsters can carry the oxygen with him or her to school or where ever they might travel. Another development in respiratory therapy is inhalation therapy which involves the use of nebulizers which force oxygen and medications down deep directly into the lungs.

6. High Tech Responses to Feeding Disorders. For one reason or another, thousands of infants cannot eat normally. They need assistance in being fed. Some of these infants cannot chew, others cannot swallow, others are allergic to foods. Modern science has developed a variety of ways of feeding these youngsters.

   a. The nasogastric tube (NG). The NG tube, as it is called, is inserted in the nose pushed down through the esophogus into the stomach. Through the tube, the child is fed specially manufactured foods which are balanced and rich in all necessary nutrients.

   b. The gastrostomy tube. Some children have a damaged esophogus and cannot eat even through an NG tube. Another choice for these youngsters involves a gastrostomy tube. This tube is inserted directly into a hole in the abdomen and liquid food is pushed by gravity directly into the stomach. Children fed this way are placed in a slightly elevated position to aid flow of fluid by gravity.

   c. Jejunostomy tube feedings. What if children are born with only a portion of their normal stomach or the stomach they have does not perform its function properly? Medical science has found a way to feed these yougsters by means of a tube inserted directly into the small intestine at the point of the jejunum. An incision is made in the lower abdomen and the tube is inserted. In this case, however, an infusion pump is generally used to carefully monitor the amount of liquid food received by the patient.

   d. Total Parenteral Nutrition (TPN). TPN involves the feeding of the child by means of liquid entered directly into the blood stream. One way that this is facilitated is with a device called a Broviac or Hickman catheter. This device remains in place inserted into a large vein and allows direct and easy

connection for feedings. Once again, a pump is used to carefully control the amount of liquid received and the speed with which it is received.

All of these techniques are available in the home setting. A few years ago anyone in need of any of the above had little choice but to remain in the hospital.

7. Glucometer and Insulin Pumps. A recent development called a glucometer has helped patients with diabetes monitor their sugar level quickly and accurately at home. The new device is comparatively inexpensive. The device is able to read blood sugar levels off of specially treated paper which is stained by one pin prick of the patient's blood. Another exciting development involves the insertion under the skin of insulin pumps which carefully control the flow of insulin received by diabetics throughout the day. This new pump allows for only a small dose of insulin to be released continuously through the day which gives the patient more even metabolism instead of the ups and downs, highs and lows associated with insulin injections.

8. High Tech Beds. One of the major and unwanted side effects associated with some long-term hospital stays is decubitus ulcers or bedsores. This is a very common problem among quadriplegics and children who cannot move. To prevent bedsores, patients must be turned at least every two hours. Failing this, the skin and then the tissue will break down. Left untreated, bedsores routinely result in infections, sometimes as serious as gangrene. Technology has developed special beds which involve matresses filled with plastic balls circulated within the mattress by positive airflow. Such beds not only help prevent bedsores, but are helpful in curing bedsores in patients who already have the problem, and prevents any further skin breakdown.

9. Blood Transfusions at Home. There are several different circumstances in which a child would require blood transfusions. The most common perhaps is anemia. Such transfusions are now given at home under doctors orders with less stress than the alternative.

10. IV Antibiotics and Other Drugs. There are times when infections are severe and do not respond to drugs given by mouth or injection. The only alternative is to get highly concentrated medication, given intravenously, into the blood stream quickly. Until recently, this required hospitalization. It is becoming increasingly more common for trained nurses employed by home health agencies to provide and supervise IV antibiotic therapy at home. The results to date have been very positive.

11. IV Chemotherapy. Until recently, a cancer patient would have to go to the hospital to receive his intravenous dose of anti-cancer drugs. Such treatments were generally given every two or three weeks depending on the particular kind of cancer involved. The effect was to give the patient massive doses of the medication which sometimes has a tendency to produce unwanted side effects. Modern science has now developed a special infusion pump which dispenses a small amount of the anti-cancer drugs into the system on a time release basis producing maximum positive effects and minimizing side effects. The tolerance level is raised by the patient's ability to be home where the nutritional balance is much better for the patient.

12. Home Dialysis. Thousands of Americans suffer from kidney malfunctioning. They require dialysis to remove waste products from their blood. Until recently such "mechanical kidneys" were only available in the hospital. Technology has now

been refined to the point where this can be done at home at a fraction of the usual cost.

13. Portable EKG Units. Some home health agencies have walking cardiac monitors available to track the heart beat over a 24-48 hour period while at home doing normal activity and rest. In addition, they have portable electrocardiograph units which they take with them to visit patients with heart problems. Visiting nurses also monitor fluid levels and medication levels to insure that patients do not lapse into congestive heart failure, a common problem among the elderly.

14. Transplants and Prosthetic Devices. While all heart and kidney transplants are done in the hospital, a greater portion of the convalescence and rehabilitation of patients is now done at home than ever before. The same is true for total hip replacements in which the patients are fitted with artificial hip joints of space age material which generally allows them excellent range of motion and mobility inplace of the ankylosed or "frozen" joints common to many seniors.

15. Ostomy Care. Some children are born without some portion of their intestinal tract. In other cases, some portion of the bowel may be surgically removed. It is often necessary in such cases to create another opening usually in the abdomen from which the waste products are routed into a plastic bag. There are generally two common types of such procedures: colostomies and ileostomies. Home care agencies commonly provide help and assistance to patients who need ostomy care.

16. New Technology for Drawing and Testing Blood. Modern technology has been refined to the point that a tiny amount of blood extracted painlessly can be analyzed within minutes for dozens of different variables. Much of this can be done at home. What used to require vials of blood now can be done with a single drop. Blood levels help determine the course of treatment and ensures the patient's progress with certainty. Agencies report the results to physicians and collaborate on the proper treatment regime.

17. Telemetry. Medical science has developed sophisticated technology to monitor the vital signs and health of astronauts while they were in outer space. This same technology now has been adapted for home use. Infants can be at home and yet hooked into major medical centers miles away where all their vital signs are being monitored. This added security allows thousands of youngsters to remain at home who otherwise would need to be in the hospital.

18. IV Morphine Drips. As a means of pain control among cancer patients or others who suffer from particularly painful injury, the accuracy of infusion pumps allows the release of small amounts of morphine over time into the blood stream. The results have been highly positive.

19. Emergency Call Systems. These systems allow the patients or their family to immediately summon help. The response systems are tied into a central place which monitors the calls on pre-assigned radio frequencies. By literally pressing a button, the family can summon immediate help. Experiments are presently underway with interactive cable television. What this means is not only that you can watch television, the television will be able to help watch you. Some people suggest that in the future, each television set will come equipped with its own camera and be capable of transmitting images and sound as well as receiving them.

20. TENS System. Medical science has developed an appliance which can be used for pain control and to stimulate the regeneration of nerve endings and assist in the restoration of muscle. These so-called TENS appliances provide stimulation in the form of a small electrical charge which is applied at intervals of several seconds causing a contraction and passive exercise of the pertinent muscles.

The above examples are merely illustrative. As time goes by, more and more refinements will be made so that additional life saving technology which is found in the hospital will be available at home. With improved design and manufacture, products will become more compact and less costly.

It is not unreasonable to expect that the United States may follow in the footsteps of certain European countries in which virtually everything we now think of as an acceptable hospital procedure is done at home including some major surgery. At any rate, the technology has already developed to the point where many chronically ill children can be cared for at home where they most want to be.

IV. CASE HISTORIES OF CHRONICALLY ILL CHILDREN

As indicated in Chapter II, chronically ill children suffer from a number of specific diseases, disorders and birth defects. Others have disabilities resulting from devastating accidents.

The following case histories, drawn from interviews conducted by the Foundation's Caring Institute, are illustrative of the breadth and scope of the problem.

STATEMENT OF MR. S. OF PHOENIX, ARIZONA ON BEHALF OF HIS SON, ALEX

Just after he was a year old, we found out Alex has a degenerative, terminal illness that's called Tay-Sachs. Tay-Sachs used to be somewhat more common than it is now. It's caused by the lack of a hex-A enzyme, and it causes a buildup of limpids. Basically, it's a breakdown of the nervous system and the way his brain functions and works.

Alex's development was progressing as a normal child's would up until about the age of seven months, and then we noticed that he was not learning new things. That's when we started trying to find out exactly what was going on.

The first thing that they told us is that they wanted to wait until the child was a year old before they did any analysis because children typically develop at different rates.

Well, we felt that there was definitely something wrong. We pursued it, and fortunately, we met up with some doctors who were in agreement with us that, yes, there was something wrong.

We had come to the conclusion that Alex was going to be severely retarded, but we did not know why. We found out through the genetics test that we took. There's a series of tests that were run for various genetic disorders and one of them was Tay-Sachs and that's when we found out that Alex had Tay-Sachs.

At the time, they were saying he would live three to five years. Now they say more like three to four because they say four is pretty old. They said that his development would reverse and he'd go back to being like a baby, which is pretty much where he is now. He can't really move much or do anything.

He can't eat on his own or drink a bottle or anything. He has a series of medications he has to take and it is difficult controlling his seizures. Some of them were lasting 25 or 30 minutes, and it was very difficult to get the right combinations of medications and to get the whole situation under control.

In the state of Arizona, there are no programs, established to support people with this type of a situation.

The only alternatives we had were if the insurance company would allow him to stay in the hospital on a full time basis, which they would not, or to make him a ward of the state, which we certainly did not want. Practically, the only option you have is to make your child a ward of the state. And it's not that you can't see them or visit them, but--

he's our baby. We don't want to give him up. They even have the option to place your child in someone else's home if they want to.

We pursued every avenue. I made phone calls for days to try to find out what types of programs might be available, and there's nothing.

Fortunately, we were able to persuade the insurance company to cover home health care for us. It is not only the best care that's available for Alex, but it's also an advantage to the insurance company. But we had to fight to get the home care. It wasn't like it's just easily provided. You've got to really get your doctors out there helping you fight for it. You have to have letters written and wait and see. There's no precedent established.

It's hard to believe that there is no program set up for children with this kind of a situation. There's no solution. They've never dealt with this before. There are no answers for this.

What if he was in the hospital the whole time? The costs would be astronomical! It would certainly be more than what his home health care is. Initially the insurance company thought they would rather have him in the hospital. They wouldn't justify having home health care.

We were fortunate because my wife happens to work for a hospital association, and has excellent insurance. If we didn't have that insurance policy, I don't know what we would do.

I have Blue Cross-Blue Shield, which covers 80 percent of total costs. In our case that's 80 percent of $200,000-$250,000 a year, 20 percent of that is still a lot. You can only afford that for so long. Even if they're paying 80 percent, 20 percent of a catastrophy like this adds up real quick.

Obviously, there's a great need for a national program. There needs to be national awareness. There have to be some policies set up and some precedents made so that when someone is faced with a situation like this they don't have to go through the red tape of pushing it through and trying to figure out what to do.

STATEMENT OF MRS. R OF CLINTON, MARYLAND ON BEHALF OF HER SON, JEFF

When Jeff was about 14 days old, he stopped breathing for the first time. I was holding him in my arms in our bed and noticed that he was not breathing. I screamed at my husband and we sort of tossed him back and forth with each other, until Rick whipped off his diaper and gave him a smack on the bottom. Finally, he started breathing again.

The next day, we were at the pediatrician's office and mentioned to him that Jeffrey had stopped breathing. He put him right into the hospital and ran a whole battery of tests.

Originally, they thought he had sleep apnea which is a condition of infants where they have periods where they can stop breathing. They place them all on a monitors which would alert a parent or whoever was taking care of them that their child has either stopped breathing or that their heart rate has dropped below a certain level and they thought this is what Jeff had.

And through the months, he progressively got worse instead of getting better and that's when they suspected that it had to be something more and that's when he gave us the diagnosis of Ondine's.

Ondine's Curse is a pretty rare syndrome. Jeffrey's brain fails to tell his body to breath at night during sleep. As he's going to sleep he breathes less and less.

He was in the hospital for about 18 months. He was in for a year and home for about five weeks. He would be in the hospital for three weeks; he'd be home for a day; he would have respiratory arrest; he would have to go back into the hospital; he would spend another month; he would be home for two days; he would arrest again; he would be back in. So finally, we just decided to keep him in the hospital.

When they decided to trach Jeff and put him to be on a respirator full time during sleep, we talked about home care. And after spending that much time in the hospital, I was very ready for it.

I was absolutely obsessed with getting Jeff home. He had spent many, many, many months at the hospital, and we realized that the hospital was raising our child. When you have a child who's in the hospital for that long, especially in intensive care or a critical care unit, you sort of lose the perspective that he is your child. You can't even give them a hug in private. I wanted to raise my own son.

So the obsession got greater and greater with getting him home and I thought of strategies of who would pay for his care. I wrote lots of letters.

The biggest problem was money. Jeffrey's insurance ran out when he was about nine months old and we were in a real dilemma because we were told that he would never have insurance again. We had a $100,000 limited lifetime coverage, and it was gone in nine months.

We tried several different companies and all of them said that with pre-existing conditions that they would not even consider us.

We applied then for Medicaid and we were turned down because we're over income. My husband has a good job and makes a good income.

I contacted the press and someone recommended Crippled Children's Services of Maryland. And two months later, we got word that they would pay for Jeffrey's care, home care, on a temporary basis. And, so far, they have continued to pay for Jeff's care. The could stop it at any time. We still owe about $800,000 that hasn't been paid by insurance. On average, it costs about $14,000 a month to keep Jeff at home. It's about $55-$60,000 a month to keep him in the hospital. That's a big, big difference; a big difference. That includes sixteen hour a day nursing coverage which we sometimes have, and rental of his respirator, his oxygen, all of his equipment and medical bills.

There's also a big difference in Jeff at home. He's brighter. He's happier. It's hard to explain how much he's grown since he's been home. He came home a docile little kid without any spunk at all. He had never been outside. He'd never seen a cloud; he'd never seen it rain; he'd never seen it snow. So when we got him home, the first thing we did was we took him out and showed him all the nature of things that people take for granted that these kids can't experience when they're growing up within four walls of an intensive care unit.

There are very, very few limits to what Jeff can do now. He goes outside; he plays; he swings on the swing; he rides his Big Wheel and eats Popsicles like any other five year old. He goes to birthday parties and goes to swimming pools and plays in the sand and fights with his brother and does everything that kids should do. He has a wonderful, quality life.

People have to understand, technology keeps these kids alive. But nobody seems to know what to do with them once they are alive, and I really think society owes them the right to be home.

STATEMENT OF DR. K, PHILADELPHIA, PENNSYLVANIA
ON BEHALF OF BABY H

We had one child in the Pediatric Unit for five years. The child's problem was very complicated. He was born in a Philadelphia hospital and transferred here several hours after birth. He was born with a congenital anomaly such that his airway was totally plugged off. He also happened to have a connection between his esophagus and his windpipe and he was breathing through his esophagus down into his windpipe. He had an inperferred anus; he had a matricular septical defect.

His mother his mother was a socio-path and spent most of the child's life in jail. In fact, she had two more children while she was in jail. So there was no family for this child to go to and we took care of this child. The child grew up here in Children's Hospital. This hospital was paid over $1.5 million by Pennsylvania's medical assistance to take care of him. They are not charges, they are actual payments.

The child grew up here and over a long period of time we were able to get him stabilized and eventually, when he was about four years of age, we found a family that was interested in taking care of him after kind of a long courtship, the family decided that they did want to take him home and be his foster parents.

Then we got into the Catch-22 of discharging him. While he was in the hospital the state was paying for him, and if he got placed into a foster home, then the city was responsible for his medical care. The cost of medical care at home was about $50,000 a year and the cost in the hospital was about $250,000 a year. And nevertheless , they were two seperate budgets. The city budget could not cope with that to the same extent that the state budget could. So we spent a long period of time until we finally had to coerce the city through media pressure to come up with the money out of is own pocket.

I do not want to malign the city government. The people that we deal with in the Department of Human Services are good caring people. They are stuck with a budget that they have to live with and part of their life is to get as much in the way of services to as many people as possible.

And they are stuck with the fact that now the child will be transferred to them but the cash flow that was previously directed towards that child cannot be transferred to them. So they are trying to do the best that they can under the circumstances, and we are trying to do the best for the child under our circumstances. It finally took the coercion of media publicity to get the city to turn around and move ahead with that discharge.

The child went home and actually spent a year with that foster family before that child died. And that was a good year for that child. The child was up and active and playing with other kids in the street, going to school and really enjoying himself tremendously.

STATEMENT OF MR. C
OF BEHALF OF HER DAUGHTER, LAUREN

Lauren is our second child. She is 6 years old. She spent the first 5 years of her life in Boston Children's Hospital.

Lauren was born in Pittsburgh. The doctors there suggested to us that we move to Boston, which we did. When we moved up there, we were fortunate in having some family close by in New Hampshire, so we moved to New Hampshire because someone at the Social Security office told us that it really did not matter in which State we lived. Lauren was going to be a recipient as long as she was a resident of Boston Childrens' Hospital; the Medicaid would be provided.

Six months after that, we were told that they made a mistake and that we had to leave our home in New Hampshire and move about 7 miles across the border into Massachusetts, where we still are. It would be nice to get back closer to our family, if possible.

Lauren is constantly infused by a pump here. She has a mal-absorption problem; it is the condition that she has and we have built this pump into a cart to get us mobile. In the hospital, this pump was connected to a large pole which restricted her from going outside of the hospital. Our daughter, is a high-tech child, a child whose life literally depends upon the machines to which she is attached.

A decade ago, Lauren would probably not have lived past her first birthday. We had another child; our first son was born with the same condition, and he died in Pittsburgh Children's Hospital at 7 months old.

Advances in the medical community have made it possible for her and many other children to survive in spite of their illnesses. Hospitals throughout the country have within them many children suffering from a variety of disabling diseases that could possibly be managed at home, but because of regulations governing payment of medical expenses based upon the family's financial qualifications, these children must remain in the hospital.

Not only would medical expenses be decreased significantly, but the quality of life of these children and that of their families would greatly improve. Every child deserves a chance to grow up at home with their families in a loving, nurturing environment, and technical advances of modern medicine have given them that chance.

Lauren's medical bills averaged $320,000 per year at Boston Children's Hospital. It is estimated that her home care will eventually cost about a third of that. Part of that cost is our nursing staff.

Lauren's care is extremely demanding, and our nurses give us a much appreciated respite from this stressful situation.

Our biggest challenge was redesigning and finding someone to build a new cart to house Lauren's new TPN equipment. Medicaid agreed to pay for a new cart because it would eventually save them from $55,000 to $65,000 per year in decreased supply costs.

At first, we hoped that New England Critical Care would be able to direct us to a medical company that would be interested in creating this new piece of adaptive equipment, but neither anyone that they approached nor any of the professional people we contacted were willing to help.

When time became a factor, we contacted another agency, Lifeline, and they arranged for a local voc-tech school to build a cart if we would provide them with the technical drawings needed. This is what we eventually did.

This whole ordeal was very frustrating. Parents burdened with providing their special needs child with the best possible equipment would benefit greatly from some type of central resource center.

Finally, and most important to us, is what would happen to Lauren if Patti and I were to meet with some accident and perhaps die. Ideally, we would appoint either my sister or her husband or Lauren's grandparents as guardians, but we are not certain that this is possible due to the fact that she is a Massachusetts Medicaid recipient under the Katie Beckett waiver and our families reside out of state.

The major problem is the disparity of benefits that each state attaches to its SSI Program. Would any insurance money or trust funds established for Lauren alter her Medicaid waiver status?

If my sister, who lives in New Hampshire, were to become her guardian, would they then be held responsible for Lauren's medical expenses? Our worse fear is whether she be made a ward of the state and be reinstitutionalized in order to continue her present quality of medical care?

What is needed here is a definite policy dealing with this issue that would provide equalization of benefits across state lines; also, clarification of guardianship responsibilities related to medical expenses.

We have worked very hard to create a home environment that would provide Lauren with the moral and spiritual foundations needed to allow her to become a mature and responsible adult. We feel it is imperative that she be permitted to continue to grow within this same environment.

STATEMENT OF MRS. R. J. J.
ON BEHALF OF HER DAUGHTER, EMILY

In October of 1985, Emily was sent home to die. She didn't.

Emily developed ectopically, outside the uterus, in the abdominal cavity--her placenta attached to the abdominal wall. She was born with multiple problems. She suffered from meconium aspiration and was on a heart-lung machine until she came home from the hospital at 14 months. When she finally did come home she had no head control and no muscle strength. She was almost like a newborn. The worst part is that we had missed so much time with her. We had so much to make up. I hadn't even gotten to hold her very much or tuck her into bed at night.

The first thing we had to do was to teach Emily to hold her head up. For a while, we were making her do a lot of things she didn't want to do. I don't think she liked to see us come through the door. At the start of Emily's care, she needed 24-hour nursing care. Emily was on a ventilator, she has a gastrostomy tube, and a tracheotomy. Because she couldn't make any noise she was hooked up to an apnea monitor when someone wasn't watching her because she could suffer from anoxia without anyone realizing it.

When Emily first came home, she gained weight so quickly we started weighing her twice a day thinking she might be retaining water. She knew she was home -- no more needles, cold hands and quick check-ups in tiled rooms full of steely machinery. Her almost uncontrollable diarrhea got much better very quickly and she started to accept larger quantities of food. And when she decided the time was right, she even took herself off the ventilator. She has learned to cope very well, very quickly.

When Emily came home her costs dropped from $56,758.50 per month to $18,000. Even with the drop in costs, she's still a million-dollar baby.

In recent months, Emily has made even more progress. She no longer has a trach. She now knows what fresh air and home smell like. Because of the trach she has never been able to talk or chew, so her jaw is immature. Also, she doesn't know how to swallow. Emily will have to learn to do these things before she can learn to eat.

Emily has gotten much stronger and bigger. Now, instead of a few wobbly tries at steps, she can make three or four confident strides. And she's learning to make many sounds that she could not do with a trach. We always knew that Emily would make it. You can tell about kids once they get home.

STATEMENT OF MRS. B OF PASADENA, MARYLAND
ON BEHALF OF HER SON, BRANDON

My husband, David, and I live in Pasadena, Maryland. We are the parents of three children--our baby daughter, Shana, and our 5-1/2 year-old twins, Brenda and Brandon.

When Brandon and his sister were born in October 1981, they were 3 months premature. We were told they had a 25-50 percent chance of surviving.

The first thing we asked was can we hold them, but the doctor said no. It was 6 weeks before we were ever able to hold them. I will never forget the first time I saw them. There were a lot of machines, tubes. The nurses had warned me that there would be a lot of these things, but I said, sure, sure. I was still expecting these chubby little babies maybe with a mask over their face, but it was not like that.

There were wires everywhere and the babies were bruised and they were so tiny. I cried. I had to turn around, although I was warned. Nothing can prepare you when you see you own babies lying there like that.

After about 4 months, we were able to bring Brenda home, with some chronic lung damage, but Brandon was not ready. He would have frequent respiratory arrest and he had to be resuscitated constantly. He would pull his tubes out and they would have to keep putting them back in, and the frequent trauma caused damage to his airways.

Because of the damage, they felt that Brandon would have to have a temporary tracheostomy. Originally, they thought there was just a lot of swelling from the trauma. They were going to put him on some special medication and in about 6 weeks, they thought they would be able to take the trach tube out. That was over4 years ago.

The doctors said there was a lot of weakness in his trachea and that it should heal, but each time that we go back, they say Brandon is not ready. We are still hoping that as long as we can maintain his airway and keep him going, eventually he will reach a point where he will outgrow this.

Modern medical technology kept Brandon alive, but medical and other support services, as well as funding mechanisms, have not kept pace with the technology. The result has been an unbelievable series of obstacles and setbacks to us in our efforts to get Brandon out of the hospital environment and into our home and family life.

Once Brandon stabilized, we knew we wanted to bring him home, but we also wanted to bring him home safely. We wanted to feel that we were not going to doze off in the middle of the night, sleep through his alarm, and find that he passed away in the middle of the night.

We wanted to know that there was somebody able and ready to respond when need be, and we could not do it alone. We wanted to know that he was going to get proper medical care. We wanted to know that he was going to get physical therapy. We wanted to know that we were properly prepared and that we were qualified to handle an emergency when we were alone and had to do it.

We wanted to make sure we had all the equipment and all the supplies that Brandon needed, but David and I did not know if we were prepared. Getting all the information and all the help we needed was a nightmare.

First of all, you have got to have a pediatrician who understands home care. If the pediatrician cannot understand that the needs of the family have to be considered, then it just will not work. That is what happened to us at the beginning.

Our first pediatrician decided somewhere along the line, because of all the obstacles we encountered in getting home health care, that we could take care of Brandon alone because we had been trained to do it. This meant that either one or both of us would go without sleep. That just did not work.

The thing that was so strange was that this particular pediatrician was the exception and not the rule. All the other people we had met who had respirator-dependent or

respiratory failure children had pediatricians who were 100 percent behind the family. They asked the families what they needed to keep their child at home, and then they wrote the proper letters to obtain it.

Our pediatrician would not do that, so we got a different pediatrician, Dr. Samuel Williams. Dr. Williams is excellent. Without him, Brandon would be in an institution today, because you have to work together to get these kids home. It is almost like a marriage -- David and me and Dr. Williams.

We had so many problems getting the funds to pay for Brandon's care at home. The financial burdens have been extraordinary. David was working for the Federal Government and although he had high-option Blue Cross and Blue Shield, no one wanted to actually interpret what that coverage entailed.

For example, we had a 90-day home health care provision which allowed for in-home health care for 90 days following a coverage admission. But no one wanted to say how much nursing care was actually available under that provision. There was a reference elsewhere in the policy to nursing care for 2 hours per visit for 50 visits.

There were some people who said that what was in that provision on nursing care applied to the home health care section as well. We could not do anything with that kind of coverage. David actually had to change jobs in order to get the insurance coverage that would help us to keep Brandon at home.

There were other problems along the way, too. When we first brought Brandon home, we did not have a reliable nursing agency. They sent a nurse without properly screening and briefing her. He did not know she was dealing with a trach baby and she was not qualified to handle him.

She caused him to go into rapid fire respiratory arrests and Brandon had to be medivaced back to Johns Hopkins Hospital. So we were facing obstacles from all sides. We could not find proper nursing care for Brandon, and in any case, our original insurance company was refusing to pay for it.

In desperation, I went through the telephone book calling every agency that looked like they might be able to help. I just hoped I could find someone who could give us the funding that we needed.

Finally, we went to the media to try to get some support, but there is a real problem out there with lack of any kind of coordinated support. We have got to get the powers that be together to decide that it is better to have a child at home; that it is more cost-effective to have the child at home than it it to keep the child in the hospital.

There is a need for agencies that can help, that can tell parents where to go to get equipment. They can help by setting up interviews with nursing agencies so that the parents can find a nursing service that can meet their child's specific needs.

There is a need for resources for parents to find out where they can take their child for developmental assessment and intervention, if need be. There is a need for a service to direct parents to good pediatricians who are oriented toward home care.

I think the existing reimbursement mechanisms, public and private, also need to be better oriented toward the concept of home care. Our child belonged at home and a lot of others who are currently in institutions belong at home. Our experience showed that it was much more cost effective to care for Brandon at home.

Yet, insurance companies that will pay thousands and thousands of dollars for care in a hospital, will not pay a fraction of that amount for nursing and other support services in the home. It just does not make good sense, and I am sure you do not think so either. But that is the way a lot of payors operate, and parents have a hard time dealing with these unnecessary barriers that are put up along the way.

At bottom, there is a lot of information that parents need to face situations like these. You do not know you are going to have a child like this until the child is here, and then it is like you are stuck in the middle of the ocean and do not know how to swim. There needs to be somebody out there with a life preserver to kind of give us a hand.

Because of all of the probelms we faced, David and I have often been asked why we ever made the decision to bring Brandon home. I think the number one reason is because he is our son, and a second reason is that nowhere else could Brandon have half the chance that he has being at home.

Institutions try hard, but they cannot care for a child the way the parents can. Now that Brandon is home, he has people he can learn to trust after being in the hospital for a year. He really did not have that there. He did not know that when he was hurting, somebody was going to come or that when he was hungry, somebody was going to feed him.

Brandon and the other children like him were being cared for and loved on a schedule. They did not get the kind of love and affection that they can get at home. While Brandon was in the hospital, he did not develop the way he should have emotionally or mentally. We wanted Brandon to have the best possible chance at leading the most normal life possible under the circumstances, and the only way we could give him that chance was to bring him home.

Now that he is at home, Brandon has made great improvements along the way, although he is still somewhat delayed. But when we think about what he would have been like if he had to stay in the hospital, there is just no way we can really make any kind of comparison because there is no comparison. Home is where he should be because that is the best place for him.

Regardless of what happens in the future, we've had five wonderful, difficult years--they've been great years. He's happy and enjoying life and that makes us happy .

STATEMENT OF JOE MILLER
OF LOS ANGELES, CALIFORNIA

We were at my friend's house and we had taken off up the street on our bicycles. I was going up the driveway and my wheel got stuck on the curb. It wouldn't go up the sidewalk. The front tire came off, clipped over, and kaboom. I was hunched over in like a racing stance when the tire came off I just flipped right over and no chance to do anything about it. I just snapped the neck.

After a few weeks in a hospital, I caught the doctor finally, and -- said-- what's the diagnosis? Am I ever going to walk again?

He said anything is possible, but that the odds are against your ever walking again.

I spent 7 months in the hospital and was bored out of my mind. There wasn't much to do, and I wasn't that big of a soap opera or TV buff. And that's about all there is on TV, and reading was out of the question, so I said, look I want to go home.

It was rough for a while, but things are almost normal now. I get up in the morning and get ready for school. And then my friends come over and pick me up and take me to school. I go to my classes, come home for lunch, go back to school and finish up the day and come home.

The biggest problem is that since I don't have nursing, my mom has to take care of me. She's not able to work anymore. We have trouble paying the rent and the other bills the rest of the world has to pay.

We filed with Social Security, and the homemaker chore program they have here in California to get help, and it's very difficult. You're not allowed to own anything, number one, because if you own anything that's of any value it effects what your income is going to be.

Then the homemaker chore, they will pay $3.69 an hour and figure I need 4.5 hours of care a day. One of the problems is that the care I need varies from day to day. I have problems where my clothing needs to be changed more than once a day, then that requires transferring in and out of bed, bathing, changing, back into the chair. If my friends are not well and they can't make it up here, then someone has to take me to school and bring me back.

The second problem is that it's impossible to hire anyone for $3.69 an hour. Rides even make $7 an hour. No one will work for that. So we're put in a position of going to welfare.

I was allowed Social Security (SSI), but because my older sister works, they consider her income as part of the household. Therefore, I am allowed $38 a month Social Security. I don't know how they come up with these figures.

I have a friend who has a similar problem. He tried to commit suicide when he lost his nursing. His mother works and he felt he couldn't get by totally on his own. He felt apparently that life wasn't worth going on.

They make it very difficult on us. They're telling us that we can't justify our needs. It's crazy because a week's cost of keeping me institutionalized is much more than the costs of caring for me at home.

The hospital bills are coming in at $18,000 a month, and that's not everything because they itemize things. Medical supplies and everything, run about $500 to $1,000 a month for my care at home.

The majority of my bills we're still receiving so far have been paid by my father's insurance and my mother's insurance. Between the two of them, they're pretty much covering it now. But since my mom can no longer work, her coverage is ending. My father's insurance will continue for a year.

After that, I don't know. It's an unknown question. I do know the bills are very, very horrendous. That will be there the rest of my life.

STATEMENT OF MRS. B OF WASHINGTON, D.C. ON BEHALF OF HER SON, ROBERT

Our son, Robert, who is 4-1/2 years old, has spent the majority of his life in three hospital intensive care units. The more recent stay has been at Children's Hospital National Medical in Washington, DC.

Robert suffers from a rare, severe form of muscular dystrophy. In August of 1983, our son was admitted to the intensive care unit of Portsmouth Naval Regional Medical Center in Portsmouth, VA. Our son was suffering from severe pneumonia and needed to be placed on a ventilator to save his life.

After several weeks at this hospital, it became apparent that in order to better care for Robert's acute needs, he needed to be transferred to Children's Hospital of the King's Daughters in Norfolk, VA. After 8 months at this hospital, it was obvious that due to his muscle disease, our son would need the assistance of a ventilator probably for the remainder of his life.

In October, 1983, we approached the staff of Children's Hospital of the King's Daughters on the feasibility of intensive care at home for our son. Considering at this point Robert had already been stabilized, there was nothing we wanted more than to have our son at home.

The staff at King's Daughters informed us at this time that neither their hospital nor the State of Virginia had the necessary resources to properly care for Robert's acute needs on a long-term basis. They also did not have experience or staffing available for intensive home care.

At that time, Robert's pediatric intensivist started inquiring of hospitals on the east coast that would have home care programs already established. We waited for a response from each hospital whether or not they would accept us. We were turned away from Philadelphia Children's Hospital and Bethesda Naval Hospital. Our only hope was Children's Hospital National Medical Center here in Washington, DC

In November 1983, we were scheduled for an in-depth interview with the home care staff. After the interview, we had to wait for the decision to be made whether or not we would be accepted. In April 1984, 6 months later, Children's Hospital had an opening and we were then accepted.

My husband, Michael, is a first-class engineman, E-6, in the U.S. Navy. The Navy graciously granted us a humanitarian transfer to Washington, DC. At the time of our transfer, CHAMPUS had agreed to endorse Robert's home care and to pay for his medical needs.

After transferring to the Washington area, we learned that they would only cover a small percentage of Robert's home care costs. CHAMPUS will pay a maximum of $1,000 a month. This amount would not even cover the rental cost of Robert's equipment, much less needed supplies and nursing care. He remained at Children's Hospital another 9 months, a total of 18 months of hospitalization in all.

The medical staff there would not discharge Robert without skilled nursing. The $1,000 maximum would not allow for this. Due to Robert's muscle disease, his life expectancy is believed to be shortened. Our greatest wish has always been to have him home with

us, his family, where he could receive the love he needs. Our son's life should be one of quality.

CHAMPUS will pay for Robert to stay in the intensive care unit, but will not provide adequate funds for home care. This makes no sense, especially considering home care has many advantages, including cost effectiveness.

Current documentation indicates the cost of home care is approximately one-third of the cost of hospital intensive care for acute, chronically ill, technology-dependent children such as Robert. In each case, there have been substantial cost savings to the State Medicaid programs, private insurance companies, and individual taxpayers.

The following is an approximation of Robert's costs. His hospital costs per day is $1,200; per year, it is $438,000, plus physician's costs.

For home care costs, his nursing care for a year will cost $54,496. That is 16 hours per day. His supplies cost $12,000 and his doctors $1,000, which makes a total of $67,496.

Every child that has a life-threatening handicap is different in many ways. No one child is alike. You cannot treat cancer the way you would treat pneumonia. The needs may be different, but they all have one thing in common. They need to be home.

STATEMENT OF MRS. R OF CHICAGO, ILLINOIS
ON BEHALF OF HER SON, PETER

Peter is the victim of a terrible motorcycle accident which occurred on September 26, 1987, while he was attending Tulane University in New Orleans. At the time, Peter was 19 years old; he's 24 now and will be 25 in June.

The night of his accident, Peter was taken to a hospital in New Orleans. After three and half weeks, he was transferred to Billings Hospital at the University of Chicago. At that time, Peter was in a semi-comatose state. While at Billings, he became fully conscious; however, he had lost all speech and motor skills due to his severe closed head injury. In December of 1981, Peter was again transferred, this time to Northwestern Memorial Hospital.

Originally, these hospitalizations were paid for by a $600,000 major medical insurance policy for Peter. By November of 1983, the hospital bills had totally depleted this policy. Of course, at that point, Peter was uninsurable. He had not been disabled for two and one half years and was therefore not entitled to Medicare.

Fortunately, he had turned 21 in June of 1983, so he was entitled to Medicaid, which helped some. However, the small amount of money received did not and does not pay for the special shoes Peter must have, the durable medical equipment, or the special transportation needed. By 1983, I had to remortgage my house, which had been paid for since 1982, in order to cover these costs. I am in the process of having to take out a second mortgage to cover more medical costs.

In August, 1983, Peter had surgery for a frontal shunt. In November, 1983, he had the ectopic bone in his hip removed. His leg had turned inward, so surgery was done to straighten the leg. He also had surgery on his arm, which proved unsuccessful because it necessitated therapy using gravity caused by standing. Because of his surgery and the cast on his leg, Peter couldn't stand.

This hospitalization lasted twelve weeks. Within three days of hospital discharge, Peter had pulmonary arrest. He was rushed to the nearest hospital, where he stayed for two days. Fifteen hours after discharge, he had pulmonary arrest again. Because of the inadequacy of care at the nearby hospital, my daughter and I put Peter in our van with I.V. bottles and drove him to Northwestern Memorial Hospital, which is approximately 45 minutes from our house. This was Christmas Eve, 1983. Peter remained there until April, 1984. He left the hospital with decubiti the size of fists at all pressure points and with a drainage in his hip. He was still unable to speak; however, physical therapy had begun.

Thanks to a friend, we discovered Manee Home Health Care, which has given Peter the capability to find a place in this life. Manee Home Health Care gave us nurses to clear Peter's skin, which they did successfully; a physical therapist who brought him from a state of total dependence to use of a wheelchair and a quad cane; a speech therapist who has made it possible for Peter to use a palatal lift; a communication expert to enable him to use a communication board; and an occupational therapist to teach Peter to cope, with minimal assistance, with all of his daily living activities. All have worked successfully with Peter.

When I learned of Peter's accident, I was told he was dead. To see the progress he has made is to witness a true miracle. And Peter continues to improve through the dedication and effforts of his therapists.

He was given a Medicare card in April of 1984. There is no more money for transportation. We had purchased a specially equipped van for Peter, but we had to sell it for the money. Peter now must rely on a Medicar to meet his doctor appointments. We have had to pay for his $190 shoes. We have had to pay for his $3,500 communication system because his words are still unintelligible. We have had to pay for his bathroom equipment, shower chairs and toilet seats. We have had to pay for his canes and for maintenance on his wheelchair, which is frequent, given the amount of usage. We are looking forward to having the surgery on his arm performed again in the near future.

STATEMENT OF STEPHEN B.
OF BETHESDA, MARYLAND

I have Duchenne's muscular dystrophy, which is a progressive disease that your muscle deteriorates and you slowly get weaker. I was diagnosed 18 years ago when I was four.

We have an HMO, Group Health Association, which pays for our nursing care 24 hours a day. It also covers most of my hospital expenses when I have to be there.

I try to stay out of the hospital. The nurses at home know me. They're friends.

In the hospital it's different. You don't really feel that way. You don't feel much like yourself. It's a very sterile environment in the hospital, and very tiring to stay there. I'm more susceptible to getting colds and viruses in the hospital and I get bored very quickly.

At home I can either call friends or draw or read. I can go outside, take a walk around the block sometimes. And then my friends usually stop by. Either one or two of them stop by usually. I use the telephone a lot. I go see a movie and sometimes even go to the beach.

I put the ventilator on the back of my wheelchair, which has a battery that can last up to three hours. And I use a portable compressor, a small unit that sits on top of the ventilator, which gives me all the compressed air and away we go.

We have a car now that has air conditioning. A special seat for me and a driver. There's usually a nurse in the back seat, and a friend who has a truck takes my wheelchair.

Some people say it is not worth living, being on a ventilator; but, it really makes a big difference. When I had to have the trach put in, we asked the doctor what to do.

He said if I were his son, he would take me home to die. I thought about it and it was no easy decision. But aside from wanting to live, I just thought I had to be there for my family and friends.

In addition to the HMO, when I was 18, I started getting some help from Medicaid. They pay for my medicine. They also have a personal care program we thought might help.

I need help dressing and going to the bathroom. I have to be turned and washed and thought they would pay to have some one come into the house to help with these things. But the maximium they pay is $10 a day. Whether you get someone for two hours or four hours, $10 is the most they will pay. I'm not sure how well it works for other people, but in this area they may have the program, but they don't have anyone to go with it.

You have to find somebody who could provide that care and then have them approved before we could get Medicaid involved with it. An so it never really worked for us.

STATEMENT OF MRS. N OF TUCSON, ARIZONA ON BEHALF OF HER DAUGHTER KIM

In 1978, Kim was diagnosed with acute lymphocytic leukemia that was in remission. We moved to Tucson the same year and everything went fine -- this is a major cancer treatment center of the country. And then in 1982, Kim developed some speech problems and we took her into the hospital. They weren't sure what it was.

By October 1982, she was admitted into the hospital and had some bleeding in the brain which had created pressure on some of the major cranial nerves -- she was unable to swallow, she had to be put on a ventilator, and they found a growth inside the brain which was so fast growing that the doctors told us that it didn't look like she was going to survive more than a couple of months.

At that point, the doctors decided they knew because of the location of the problem on the brain stem, that there really wasn't anything they could do in the way of treatment for Kim. It was devastating; a real shock. All they could do was provide supportive care. When they gave us the news that she had very little time to live, it was just our gut feeling we wanted her home. I felt like we only had one chance, and I didn't want to do it wrong. We didn't know the hospital had never done that before. We told them we wanted to, and they worked on it, and they helped us.

The day before Thanksgiving in 1982, Kim came home. We've got a Golden Retriever that's very rambunctious and kind of jumped up and gave her a slurp -- and that was her welcome home! Once she got home, the changes were very quick.

At first she was unable to even be rolled up on an incline for a short period of time without getting tired and in pain. By Christmas time, she was able to sit up in the wheelchair. We took her in for a follow-up visit. They found a second tumor and that the first one had actually gotten smaller in size. She was obviously doing much better. We wanted to go to Disneyland as a kind of a last family thing -- and we did.

She was still in a wheelchair, still on a respirator, and so we had to take all the equipment she was on on the road. We also took her nurse with us. It was fun. Kids get on Space Mountain and -- you know-- they all scream. Kim had her trach, and so she just put her finger over the hole to scream like all the rest. It was great.

She was in the first grade then. The first week she went back to school, we just went over to visit, to let her classmates get used to seeing her with her wheelchair and her equpment that she needed with her. Kim had an exceptionally good first grade teacher. It was a good experience for the other children, too.

Kim was back in school full time by second grade. She's progressed quite well and seems to be keeping up pretty well with the kids. Her handwriting is a little slow, so she needs extra time to do some of her homework.

Today, Kim is in the fifth grade. She receives speech and physical therapy three times a week after school, at home. Having the therapists work with her at home leaves her more time to play with her friends, and this way, it doesn't interrupt her normal life."

STATEMENT OF MRS. N OF CLEVELAND, OHIO ON BEHALF OF HER DAUGHTER, JESSICA

Jessica entered this world four months ahead of schedule at twenty-four weeks gestation; she was a tiny handful, weighing less then a pound and a half. Born so early, Jessica was not able to eat or breathe on her own and required high-technological medical intervention to save her life.

The term "medically fragile child" projects such a sad picture of a tiny frail baby that I'm sure we have all questioned the advances of medical technology and intervention in the quality of life.

But, Jessica shows to those around her the meaning in each and every moment of her life. She is now thriving and with great care going beyond survival.

When we first brought Jess home, it was with the thought that we could only make her possible death at home more comfortable and that we would strive to make each precious day in her life a happier once at home with her family.

In spite of her problems, she continues to fight for her life; she enjoys each and every achievement and special moment.

Jessica, now three years old, has chronic obstructive lung disease and bronchopulmonary dysplasia, in addition to physical and developmental delays. She has a tracheotomy and receives oxygen and numerous medications with round-the-clock

monitoring and therapy treatments for her lungs. Twenty-four-hour-a-day nursing care is also required.

While Jess has lived, other very special friends have died because the children and their families were not given support. We know them and their struggle, and with their love still lingering in our hearts, fight to go on in their behalf as well as outs.

Prior to Jess's discharge from the hospital, I checked with my company's personnel department to find out what benefits were available to bring her home. I work for AmeriTrust company, a bank that is progressive and a forerunner in expanding employee health care benefit programs.

For the first two months, we used a nursing agency to provide round-the-clock nursing care. The cost of these agency nurses was sometimes $29.00 per hour. At that rate, Jessica's care was totaling approximately one-half to two-thirds the cost of her care in the hospital. In order to stretch what health care dollars Jess had left, Sandi and I decided to hire nurses directly. Ameri-Trust's child care referral department helped submit newspaper ads for nurses.

It was coincidental that many of the nurses who responded to my ad had been employed at the hospital where Jessica had spent so many months of her life. A few of these nurses had even cared for her while she was in the neonatal intensive care unit.

My company allowed me to "save" my maternity leave for Jessica's discharge from the hospital so that I could spend time with her once she came home.

Jessica's lifetime major medical expense was quickly reaching the maximum. We knew that if funds were not found for her home care, the only alternative would be a hospital or institution.

I started a letter-writing and phone call campaign to convince government agencies that Jessica's home care was less than half the cost of institutional care. We did a cost-benefit analysis that we submitted along with pictures of Jess, statements from her doctor, and my personal appeal to continue Jessica's care at home with her family. This information was submitted to President Ronald Reagan, the Health Care Financing Administration, the Ohio Department of Health and Human Services, and local congresspeople and senators. This was followed up by constant "reminder" phone calls. Some days over twenty calls were made, with no-one giving any hope for my plea.

After almost six months, we finally found someone willing to give hope to our actions. Her name is Loretta Kallipolites, coordinator of Ohio's Model 50 Waiver program. Loretta was instrumental in getting state approval, while the wheels of government were slowly moving to finally get federal monies. I have recently been assured that Jess's health care needs will be met by matching dollars from the state and federal Medicaid funds.

When Jess came home, she couldn't even hold her head up or roll from side to side. There was no way for her to communicate her wants and needs, and because of the trach tube, she could not speak. There was one small thing I always wanted for myself, and that was for Jess to say, "Mommy, I love". I felt that would help me go on. Now she tells me, her daddy, and her many nurses that and so much more with sign language and is learning her alphabet and numbers. She can form simple sentences and has learned the motions to her favorite songs. She can sit independently and considers herself "a big girl". She is becoming potty trained and has recently taken her first steps with a little help. Her health is improving and she will be in a preschool program this year for special children like her. In her near future is possible reconstructive

surgery to rebuild her weakened trachea. This would allow Jess to speak with her voice.

Jessica has made amazing progress far beyond anyone's expectations. Today we are enjoying our happy, thriving, little girl and have had so many previous days behind us that cannot be taken away. As a family, we look to the future with Jessica as a welcome joy as she shows to us the value of each day shared as a family.

STATEMENT OF MRS. S. OF SEVERNA PARK MARYLAND ON BEHALF OF HER DAUGHTER, ERIN

When Erin was born, on the 21st of November in 1979, she was born crying, and she didn't stop crying for hours. And I remember very vividly asking, why is she not happy? She started to wheeze in the beginning just intermittently, maybe five or ten minutes a day. And her color wasn't quite right.

At age four weeks, she was doing it more frequently, but she would be fine when we got to the physician's office, so no one actually saw her when she was in trouble. We visited at least three physicians a week from when Erin was four weeks old to nine weeks old, going from clinic to clinic, hospital to hospital, asking different physicians if they would help us pinpoint what Erin's problem was. It took us until she was nine weeks old to find a physician who didn't just say, "Gee, she's too tiny. She's toos fragile. We can't help you," or "Gee, she's alright, she shouldn't be here.

This physician determined that she had a floppy larynx which means that the air coming through the trachea gets kind of trapped, and so it can cause wheezing. It can cause minimal respiratory distress. But the feeling was that she should be fine, that she was tiny, and that hopefully within a matter of weeks, months at most, it should resolve itself with her airway strengthening up.

We saw the physician every week from that period until Erin was about 14 weeks old and it did not appear to be resolving. In fact, it was perhaps getting a little worse. So the doctor recommended that we go as an in-patient and do a bronchoscopy and a laryngoscopy. After the procedure, the physicians came out and said that they really felt encouraged that her airways looked very normal. They said we should wait about six hours in the recovery room to make certain there are no problems with the anesthesia, and then we can go home.

Well, there appeared to be some problems. Within 12 hours after she had the procedure, she was in intensive care. Within 18 hours, she had to be intubated and within 24 hours she was on a ventilator.

The only real reasoning they could come up with was, that because of the uniqueness of her airways, the procedure kind of tipped what we would have been dealing with weeks down the road. She has tracheal bronchial malaise, which means that the cartilage in her trachea and in her bronchus is not completely developed and formed. It gives way to collapse.

On the fourth day following the initial procedure, she had an emergency tracheostomy performed, and even with the tracheostomy tube, there was still something wrong.

She was in the hospital about a month, and they felt that they had stabilized her condition. We had an artificial airway for her and as long as we kept it open and clean we should not experience any acute onset of any kind. Hopefully, within a matter of 6

to 12 months, we could look at decannulation, and that she should be fine. Because that was the history of this kind of disease, as far as they could tell from the medical books.

Unfortunately, her condition continued to deteriorate. We were home for about 10 days when she obtained a very bad infection. She had to be placed back in the hospital.

It was another emergency transport into the emergency room and then into PICU (Pediatric Intensive Care Unit). They decided to do another bronchoscopy, because they felt that there had to be something else there besides just weak airways, but she was too sick at that point to do it.

We came home for a few days, having another admission already scheduled. They did another brochoscopy, and they found another larger area of collapsed trachea. They did an endiogram to see if there was something acutually holding the trachea closed. It did not give any answers. They didn't know. It was obvious that whatever we were dealing with was progressing.

Erin has been home for about 5 years, now. We used to have to ventilate her manually; all night long to keep her airways open because they said that there was not a ventilator that could be adapted for home use. How could we adapt what was traditionally only in the hospital? We had to do that by hand. One of those nights, we weren't as successful as we had been previously. That was the risk we took to have her home and we knew it.

That particular night, she was about 2-1/2 years old. It was bout 3:00 a.m., and we had been experiencing a severe rainstorm. The power went out. We have all the backup equipment that everyone thinks you might need, except we don't have a generator.

Well, Erin totally collapsed. We lost her heartrate. We were using all these wonderful flashlights and spotlights totally illuminating her room, when the power went out. We had nothing. And she went into cardiac arrest also. We had to pick her up from bed, put her on top of the cardiac board which we have underneath her bed. We started doing chest compressions. We had a candle in the room with all the oxygen which is dangerous, but it was totally dark. We couldn't see.

We kind of rehearsed this before, because we tried to make certain that is anything happened, we'd already asked all the"what if" questions. My husband was calling the paramedics. My oldest son was driving the car underneath the window. We had put a long extension cord together to try to be able to have power in case something like that happened. We couldn't open her airway. That was the longest 10 minutes of my life.

Finally, she woke up and she opened her eyes and she started screaming. So at least we knew she was getting some kind of oxygen, but she arrested again. And we went through the same thing again for another 8 or 9 minutes. If something could go wrong, it went wrong. The irony of the whole thing is that as soon as the paramedics got there, the lights came on, she woke up --all at one time.

Nowadays, we have 14 hours of skilled nursing care at home. This way, we have our nights covered and our days covered, when I'm working or doing something else that takes me away from Erin. She's 5-1/2 years old now. She's on the ventilator all night. She goes to school every day half a day, Monday through Friday. Either I or a nurse goes with her. Erin arrives back home at approximately 11:30 a.m. At that time, she will be placed back on the ventilator, so that we can pop her lungs back open and give them the ability to stay open. And the rest of the day pretty much varies. She might

fo to the library. She might have a little friend in. She might go over to a little friend's house. On Friday she goes to ballet. Right now she is preparing for a recital.

The cost in terms of time and dollars is incredible. Erin has used up close to $2 million in her lifetime. We have gone through three insurance policies. But the outcome is something close to a normal life for Erin.

To me, this is an accomplishment. She goes to the same school that her three brothers have gone to. They've all had the same kidnergarten teacher. And she is able to do something that every little girl traditionally does, and that's go to dance class.

D. THE NEED FOR PEDIATRIC HOME CARE: AN EXPOSITION OF ISSUES

In the process of preparing this report, dozens of in-depth interviews were conducted by Caring Institute staff with those who provide care to technology dependent children. Family members, physicians, nurses, therapists, social workers, and others involved with the day-to-day care of these fragile infants were asked for their views.

The interviews were conducted in 10 states - Arizona, California, Connecticut, the District of Columbia, Illinois, Maryland, Michigan, New York, Pennsylvania, and Virginia. These 10 states account for roughly half of all the nation's expenditures on health care. They account for about 50 percent of both the Medicare and Medicaid programs.

Our analysis of these interviews are excerpted here. The authors of this report were amazed at the similarity of the responses. There was a high degree of consensus among those who were interviewed on almost every issue.

This consensus is reflected in the comments and conclusions that follow.

A. MOST COMMON DIAGNOSES OF CHRONICALLY ILL CHILDREN WHO ARE CANDIDATES FOR HOME CARE

According to the medical experts interviewed, the longest single category of chronically ill children results from premature births and low birth weights. Some of those interviewed indicated this factor could be responsible for as much as two thirds of the total. Others were more conservative, but almost all agreed premature birth was a contributing factor in at least 50 percent of all cases. The majority of the remainder are babies who were carried full term and yet developed congenital anomalies, such as asthma, cystic fibrosis, immune deficiencies, and the like, and accident victims.

A good number of the children have feeding problems, problems with their cardio-vascular system, juvenile diabetes or neurological diseases such as muscular dystrophy.

The challenge for medical science and caregivers is that chronically ill children are likely to suffer not only from one of the above, but more likely they will face three, four or five major problems. As Dr. William Purdy noted, they are twice or three times as complex to manage as are normal children and they require a good deal more time and attention.

One of the most rapidly growing classes of chronically ill children are those with AIDS. According to the Center for Disease Control, there were only about 400 confirmed cases of pediatric AIDS in the United States as of January 1987, and about 60 percent of these children have died. The care of AIDS patients is a major challenge to the health care system, even more so when it involves children. Since such a high percentage of these children die, the case of pediatric hospice care becomes stronger with each passing day.

B. ADVANCES IN TECHNOLOGY CREATED THE PROBLEM AND ALSO HELPS DEFINE THE SOLUTION

The development of modern technology has helped save the lives of thousands of infants who previously would have died. Just twenty years ago, infants born premature with birth weights at three pounds or below were not given much of a chance. Today infants with birth weights as low as 2 pounds are given a better than even chance to survive.

This life saving technology, which is comparatively new to the hospital, has in recent years been made smaller and more portable and converted to battery operation.

It was the consensus of those interviewed that similar advances in technology will continue to occur into the forseeable future, making it possible for still other thousands of youngsters to survive.

The basic problem with respect to chronically ill infants is that the policy has not kept up with the changes in technology.

According to Dr. Robert Kettrick, the real challenge is not just to save and extend the lives of these youngsters, it is to extend good quality life. He said the technology turns out to be the easy part. "The difficult part is developing social systems to allow these children to have a good quality of life given that they are attached to the technology."

The physicians interviewed agreed that technology and the provision of medical care to the chronically disabled infant population was a good investment in the future of the nation. They noted that many times such infants outgrow their dependency on the technology and lead perfectly normal lives. They note that society has no choice but to care for and assist such youngsters, particularly since it is impossible to tell which of them will grow into a future scientist or leader of the nation.

C. THE PRIMARY EMOTION OF PARENTS WITH A DISABLED CHILD: FEAR AND FRUSTRATION

From the moment a child is born with a disability, the lives of the parents are changed forever. There was a consensus among those interviewed that the primary emotions during the hospital stay were fear and frustration.

Mrs. Brenda Buckholtz puts it this way:

> "I was horrified. I was expecting big healthy bouncing babies, not miniature size. And what I saw was a shock. I mean there were machines going off everywhere and they were so tiny, and their skins were transparent so that you could see their veins.
>
> "I was terrified. They had wires everywhere and they were bruised... I couldn't stay. I cried. They had explained to me what I was going to see, but nothing can prepare you when you see your own babies lying there like that."

Some parents continue to live in fear even after the child is sent home and is receiving home care services.

Asked if he was afraid, Mr. Donald Oaks responded:

> "Yeah, I was at first. Like the first time we changed the trach ourselves here at home. It was scary".

Mrs. Michelle Barclift said, "I was thrilled to death to know that he was coming home and at the same time terrified because I knew there were going to be a lot of things that had to be done and I am not a nurse."

Mrs. Sandy Reckeweg said:

> "I was afraid I wasn't going to be able to handle it. The first time Jeff came home, I was his only caretaker. My husband was gone for seven months, doing work out of town during the week. So I was Jeffrey's only caretaker plus I was caring for his older brother."

Mrs. Angie Bachschmidt answered along the same lines adding, "There was no one I could turn to to help me...it was awful."

Mrs. Margaret Mature agreed by saying she was "terrified." When asked why, she said: "Well, there were a lot of responsibilities and we had to learn how to take care of him. He was on quite a bit of equipment, and he was on it 24 hours around the clock...so there were a lot of things that we had to learn."

D. CRITERIA TO BE USED TO DETERMINE WHEN A CHRONICALLY ILL CHILD CAN BE DISCHARGED INTO HOME CARE

There was agreement among the medical and nursing professionals interviewed as to the criteria which should be used to determine when a chronically ill hospitalized child was ready for home care.

They emphasized five essential elements:

1. A child must be medically stable. One doctor put it this way, "If a child is medically stable, then you can move just about anyone of them home."

2. The transfer of the child to the home care setting must offer the child an improved quality of life. It should afford the child an opportunity for growth and development which is not possible in the hospital--an opportunity to lead as normal a life as possible under the circumstances.

3. The transfer of the child to the home care setting must be an acceptable risk. It must be safe. Whatever risks there are must be small enough to be offset by the advantages of having the child home.

4. The family must be fully informed and willing to take on most if not all of the child's care. Some experts were of the opinion that this was the most important factor of all. Said one expert, "The family's love and support and its willingness to take care of the child is the key factor to be examined."

5. There must be adequate community support available. No family can provide by itself all the support that the child formerly received in a hospital. The child will continue to need medical and nursing care, therapy of one kind or another, equipment, drugs, supplies, and other assistance. The family itself will need reinforcement and encouragement. A decision must be made that these supports are in place with in the community.

Commenting on the above, Dr. Shabino said, "We look at every child as an individual and every program is tailored very specifically for this child and each family."

Dr. Hartline agreed, and said "the most important element is people who are committed," he said.

Ms. Nancy Weinstock, then co-director of Children's Hospital National Medical Center Home Care in Washington, DC, summed it up by saying: "I think the child must be medically stable so that it is safe for him to be cared for at home. He has to have a family who is able, both intellectually and emotionally to take care of him at home, and there has to be the support in the home and in the community which allows that to take place."

E. MOST FAMILIES WANT THEIR CHILDREN HOME: ARE THERE TIMES WHEN CHILDREN SHOULD NOT BE SENT HOME?

The consensus of the experts is that most families want to take their children home with them. Dr. Kettrick said it best:

> "It takes a lot of fighting and scraping to get that put together, but once those funds are available, most families will in fact take their children and are so pleased with having them home that they will not bring them back to the hospital".

Assuming the child's medical condition is medically stable and the family is willing, the child should almost always be sent home if adequate community support is available because the benefits of having the child in the home environment are so substantial. Dr. Shabino expressed the consensus that "occasionally, you will find a situation at home which will not be conducive to sending the child home, but this is the rare exception."

The key determinant in the decision not to send a child home in the rare instances when such a decision is made is the family itself. There are a small number of families who either cannot or will not cope with the burden of caring for their chronically ill children.

F. MAJOR OBSTACLES TO HOME CARE FOR CHRONICALLY ILL CHILDREN

There was a clear consensus as to the major impediment to caring for chronically ill children or severely disabled at home. The obstacle listed first by most families was lack of funding. Families spoke of the lack of funding support from any and all sources: states, private insurance and the federal government.

Mrs. Connie Fischer of Michigan said: "I just feel that there are so many barriers to the issue of home care. I feel like we live in this high tech age and children are being kept alive in neonatal and all this progress that we are so excited about, has brought us special problems...No matter where you turn there are barriers whether it be financial or even if the finances are there, the services are not available for purchase."

Mrs. Fischer told the House Subcommittee on Health and Long-Term Care that her daughter does not qualify for Medicare, that they could not qualify for Medicaid because their income level was too high and that though their private insurance would pay for 364 days of care a year in either a hospital or a nursing home, their home care coverage was limited to $10,000 a year.

Mrs. Michelle Barclift said that this situation puts "people in a position of literally becoming liars in order to survive." Many families have to divest themselves of assets in order to qualify for benefits under the Medicaid program.

Dr. Richard Lemon said, "One of the largest obstacles is funding. We have large increases in the technology and the science of medicine. The application of science is expensive."

Problems in trying to obtain financial help forced the Bachschmidt family to move three times into three different states in the first two years of the life of their chronically ill child.

Mrs. Karen Shannon agreed that funding was the number one problem: "Funding is the biggest challenge, because if you don't have the funding, you do not have the ability to give your child the quality care that he/she needs."

Dr. Shabino had this to say: "Finance has been the major stumbling block in trying to get these kids into the home setting and it is very frustrating at times because we know from a medical and from a social standpoint that home is the best place for the child to be."

When asked about the burdens of caring for his son, Mr. David Buckholtz said, "The burdens basically have been financial and emotional...the financial burden has been extraordinary to say the least."

Mrs. Reckeweg said that funding was "the biggest and really the only major problem" that their family faced.

Dr. Hartline also listed funding as the major obstacle. He offered examples of insurance companies that would allow children to stay in the hospital until they had exhausted the upper limits of their policy's coverage rather than spend far less to care for the kids at home.

Dr. Kettrick said that the problem from the point of view of state and the federal governments springs from their experience with entitlement programs, which in some instances have become very expensive. He went on to suggest that there should be a federal entitlement program for technology dependent children and for children with chronic diseases. "I think that would be good for society, it would be good for the children and good for the economy."

Dr. David Hirsh said that part of the funding problem is that some policy makers ask: How can you justify the use of scarce resources to care for chronically ill children many of whom have short life expectancies? Dr. Hirsch's response was:

> "Who's to say who's going to live and who's to die. As a physician, and I think most physicians would agree, I just want to enhance the quality of life whenever possible and a lot of the time, we don't know what the final outcome will be."

Most physicians agreed that it is very difficult to predict the degree of development of a child. Moreover, no one is arguing that euthanasia is an acceptable alternative. Given this fact the choice is limited to: (a) neglecting a child by withdrawing support, (b) keeping the child in an institution, or (c) maintaining the child at home. Since (a) above is really a passive form of mercy killing, the only real choice is whether to care for the child in an institution or at home. When this is the choice, the care of the child at home has every advantage from the point of view of society as well as the child and his family.

When asked to list other obstacles, several people listed prejudice of physicians and hospitals as a major factor. Mr. Bachschmidt said of one physician:

> "He told us we were crazy. You don't know what you're asking for and he said that this is something that will totally ruin your family."

Mr. Bachschmidt added that the attitude on the part of the hospital personnel was similar. "They didn't even mention home care until we started asking can we bring him home. At that time we were pretty much told that we might as well give it up. That it was a fight that we couldn't win."

Mrs. Mature made the same point: "A lot of people told us that we were crazy for trying it." She extended her answer to include friends and relatives who advised against trying to bring their youngster home.

Several of the physicians stressed that the technology which allows these youngsters to be cared for at home is fairly new and needed greater emphasis within schools of medicine. Many physicians are not familiar with it and do not understand the degree of sophisticated care which can be offered in the home setting.

Another obstacle mentioned was the lack of properly trained nursing and support staff. This was described not as a general problem but one affecting certain parts of the nation. Nevertheless, almost all parties agreed on the need for greater education of nursing personnel on the care of technology dependent children.

6. MOST MAJOR MEDICAL PLANS SOLD BY COMMERCIAL INSURERS ARE INADEQUATE PROTECTION FOR TECHNOLOGY DEPENDENT CHILDREN

For the most part, families who were interviewed were quite negative about their insurance coverage. They felt that the policies were inadequate and that they were interpreted more restrictively than required. Some insurance companies were praised in the course of the interviews, but these were the exceptions.

One of the insurers praised was Blue Cross/Blue Shield of Pennsylvania. Dr. Kettrick said that they have "uniformly covered" ventilator-dependent children. "We came away with an arrangement with Blue Cross of Pennsylvania that by and large allows us to take care of ventilator-dependent children at home."

The AETNA Life Insurance Company on the whole received high marks for their individual case management program (ICM). In the words of AETNA's Dr. Thomas Culley, the ICM program allows the "physician and health care personnel to tell us what sort of level of

care the patient needs and then we can modify ourselves to meet the patients needs rather than having to modify the care to fit predetermined programs.

Most of the families interviewed were less enthusiastic about their insurance policy. Mr. Scott Russell said he knew of a child who "has exhausted about $1 million of insurance sitting in the hospital waiting for the company to see the light."

Mrs. Deborah Young said that her son had already gone through an insurance policy worth about $1 million. In other words, the policy had a lifetime limitation on what it would pay to any one individual of $1 million, and the child reached that level in the first year of his life. As a result, he would no longer qualify for insurance with that company and depending on the time frame and the extent of any pre-existing condition, might not be able to purchase insurance from any other company.

Mrs. Reckeweg said that "Jeffrey's insurance ran out when he was about nine months old, and we were in a real dilemma because we were told that he would never have insurance again."

Mrs. Shannon said that her daughter, Erin, has been covered not under one, but three separate policies:

> "My husband's company has changed carriers three times. That has been, basically, our saving grace. That's why we've been able to have so much covered, because each time the insurance carrier changes, then you're able to obtain whatever their maximum is. So the first one covered approximately $1 million. The second covered about a half, and then we're at about $200,000 or $300,000 on this policy."

Mrs. Fischer had a policy that provided home care until that policy was changed. It still provided unlimited hospital coverage up to 364 days a year, but capped any payment for similar services at home at a maximum of $10,000 a year.

Mrs. Fisher asserted that insurance companies are playing a cynical game in that they are betting families won't leave their children in the hospital. She claims the companies are gambling that families by and large will want to take their children home at any cost--even if it means settling for meager payment under the terms of a policy.

Mrs. Russell said:

"You are really faced with a choice whether to leave your child in the hospital where all the bills are paid, or whether to bring him home and all that entails knowing that it's better for your child and better for your family and pay in my case, four and a half times my income out of pocket and pay for the insurance besides. I'm bringing this kid home no matter what and if I have to quit my job and lose my insurance, she continued, we'll have to do that because it's too important to leave him in the hospital."

She said that dealing with the insurance company was the greatest frustration they have had. "We had to get a lawyer to get our home care bills paid. We still owe over $100,000 worth of bills that...the insurance company is supposed to pay, that they have shredded, ignored, and they will not even let us talk to anyone in the company about the situation. I would say that has been the biggest stress."

"It is like banging your head against the wall..all that we need is the financial stability from the insurance which is what you pay for insurance for; to be able to have him in an appropriate setting at home where he's cared for in safety and not by two zombies who have been up all night."

Mrs. Fischer summed up the experience of many parents with the words: "It's not in the contract. Their excuse for not paying becomes, 'it's not in the contract'."

H. PROLONGED HOSPITAL STAYS POSE SIGNIFICANT PROBLEMS FOR CHRONICALLY ILL CHILDREN

The experts interviewed in the course of this study were in agreement that a hospital is no place for a child to live. Even under the best of circumstances with the best possible care, a prolonged stay in the hospital will mean the child's development will be hindered and the family will be torn apart.

Having the child in the hospital inhibits bonding with his or her parents, it produces stress, and sometimes leads to medical complications which result from the very fact of hospitalization.

Some of those interviewed also suggest that keeping a child in a hospital who could be home is a violation of his or her civil rights. By analogy they argue that the U. S. Supreme Court has ruled in cases of individuals held in mental institutions that they have a Constitutional right to care and treatment in the least restrictive environment. They believe the constitutional principle will be applied to chronically ill children with even more force.

1. Development Hindered

The key element in this litany of concerns is the development of the child. Dr. Culley of AETNA emphasized this point: "The home is so important to the child. The continued growth and development of a child can be hindered by continued hospitalization."

Dr. John Finnegan said that children who are hospitalized over the long-term are "years behind" their counterparts in development. They may also develop strange aberrant behavior to get attention."

Mr. Bachschmidt talked about his son's experience: "I do not like to say it, but before he came home, he was a vegetable. He had no knowledge of anything. All he had seen were four walls. The only window he had was a big bay window so that the nurses could see him. He was in an isolation room in the intensive care unit."

He contrasted this experience with results a few months after the child was sent home. He said, "Ask him where his eyes are, ask him where his nose is, ask him where his ears are and he can tell you. Before he couldn't. Ask him to say love. Ask him to give you a hug and give you a kiss. He'll do it. Before he couldn't."

Mrs. Deborah Young said her child suffered from virtual sensory deprivation having been in the hospital so long. She said that when they brought him home they showed him a tree and that "he was afraid of it at first." Other parents talked about the fact that in the hospital the children were deprived of sights and smells and sounds which are absolutely necessary to their growth and development.

Mrs. Buckholtz summed up the feelings of many parents in response to the question of why they brought Brandon home:

"I think the number one reason is because he is our son. The second reason was because nowhere else could Brandon have half the chance that he has being at home. Institutions try hard, but they can't care for a child the way that parents can. They can't even supervise him the way parents can.

He wouldn't develop mentally. They just can't give each child all that they need emotionally and developmentally. There are just not enough people to do that.

All we wanted for Brandon was for him to have the best possible chance to leading a normal life under the circumstances, and the only way we could do it was to bring him home."

Mrs. Barclift said the biggest problem she had with her youngster being in the hospital was boredom, the lack of mental stimulation--"For her and for me. Those blank faces. There was no give and take, no life."

Joe Miller, an accident victim, was asked about being in the hospital over the long term and his psychological attitude. He responded: "I was bored out of my mind."

Mrs. Bachschmidt said that Robert was left to lie in bed by himself day in and day out. "He was in the intensive care unit and he was in this isolation room all by himself...the only time Robert ever had company was when he needed to be fed or have his diaper changed. There was no communication there."

2. Bonding Inhibited

A number of experts made a specific point that prolonged hospitalization acted to prevent bonding between the parents and their child. This fact, they said, has severe implications as far as the future development of the child. Acceptance as part of the family unit, said the experts, was vital.

Dr. Shabino said bonding is difficult if not impossible while the child is in the hospital: "They are never separated by themselves. In other words, there is always somebody else running around and interfering such as the nurse and the medical staff. It is not the same as having the child at home."

Mrs. Oaks said: "All the time that Melissa was in the hospital and they were caring for her, there was always a separation between us and I never really felt like I was her mother. There was that separation. Once I brought her home and they let me have her, I felt like she was mine again, and the whole feeling between her and me was just--I'm really thankful. I can't imagine what it would be like if we didn't have her home."

Mrs. Reckeweg said: "I was absolutely obsessed with getting Jeff home. He had spent many, many months there and we realized the hospital was raising our child. When you have a child who's in the hospital for that long, especially in the intensive care unit, you sort of lose your perspective that he is your child. Because you can't even give them a hug in private. You always feel that the door has to be open. I wanted to raise my own son."

Mr. Ralph Clary described his experience his way: "Before he came home, people would ask 'what is it like to be a parent?' I really had trouble answering the question. I wanted to be optimistic and to say all the right things, but I didn't feel like a parent. It just wasn't in me. I just said the usual things, but I felt like a visitor and not a parent. Then when he finally came home, I finally felt like a parent and all that goes with it. I started thinking about the responsibilities and the joys. It was wonderful. It was wonderful."

3. A Hospital Can Be a Negative Environment

It was the consensus of experts that for all its life sustaining talents, a hospital can be a dangerous place. Children with tracheostomies are highly susceptible to infections. Hospitals may expose children to much higher risks of infection than if the child lived at home.

Psychologically, a hospital can be depressing, especially if one's stay there is long term. Mrs. Barclift put it this way: "The hospital was really depressing for him. The stay was seven months, which was a long, long time. It was far away and it was difficult for his friends to get there."

Stephen Brown, who suffers from muscular dystrophy, described the difference between being at home and being in the hospital. "When I am at home the nurses know me and they're my friends. In the hospital, it's different. You don't really feel that way. You don't feel much like yourself. It is a very sterile environment in the hospital and very tiring to stay there. I am more susceptible to getting colds and viruses in the hospital than I am at home."

Ms. Bachschmidt said that Robert's "leg got broken twice in the hospital just in changing his diaper. It hasn't happened since..the care he got was good care. It's just better at home."

Mrs. Clery said the hospital was a negative environment psychologically for both parents and their children. Asked to describe what it was like, she said it was very trying. She spoke first of the problems fighting traffic going to and from the hospital. "And then you're in there watching other babies dying or watching other babies go through all kinds of treatments and things to keep them alive...it is just very hard to sit there and watch all those other babies going through all these terrible things that happen to them."

Mr. Russell described why he believes the hospital was a negative environment for his youngster this way:

> "In the hospital the parents are visitors, which is an odd situation. You're really not raising your child. You're subject to the hospital's rules. It's the hospital's authority structure that determines what will happen to your child, not the parent.
>
> As far as the child is concerned, I think--I'm not certain--I can speak to when he was an infant. The environment is not, I don't think, real suitable for an infant. In the hospital, Daniel -- his world was just a little area. He was on an eight foot long hose. So he's just in his eight foot long semi-circle around. He lived in his crib. He spent most of his time there. Everything and everyone came to him in this little area, the doctors, the nurses, parents, lunch, dinner, medicines. Everything was brought to him in his little area in the hospital. And he lies on his back in the crib most of the time or an adult would hold him in their lap.
>
> At home, he can go into different rooms. He can be -- you know-- in the kitchen while you're making dinner, watching you work. He can crawl on the floor. His world is just much exapnded here."

Mr. Buckholtz added:

> "In the hospital, you had children in isolation who would cry as long they wanted, but they were being fed on a schedule. They were being cared for on a schedule. They were being loved on a schedule.
>
> "The thing is that with hospitalization, you just don't have the one-on-one type of care. You don't have the kind of love that you need. With Brandon, well, he was being pulled around in a little walker. He wasn't walking for himself. No one could challenge him to try to stand up for himself except on rare occasions."

Dr. Kettrick offered this comment about the relative safety of hospital care versus home care:

> "The home can be just as safe and perhaps safer than it is in the hospital. There is no question in our experience that if we transfer ventilator dependent children to a home environment, the frequency and severity of infections goes down tremendously. The hospital is a dangerous place to be if you have a tracheostomy or an artifical airway, or need a ventilator because you are now exposing the child to a community that tends to get patients with rather bad infections."

HAVING A CHILD IN THE HOSPITAL PUSHES FAMILIES APART

In addition to inhibiting bonding, having a sick child in the hospital for a prolonged period can have adverse effects on the family.

Mr. Clary said it this way: "We were trying to take off work as much as we could to get down to the hospital, and really it just completely turned our lives upside down for that period of time, and we weren't happy with the way everything worked out."

Mrs. Russell talked about how difficult it was not to be able to have her family together for Christmas. "In the scheme of things, we were glad to have him alive, but it hurt so much when one of your children is so sick that you can't even be together for the holiday...even on Christmas only two adults were allowed in the hospital with him at any one time. We couldn't bring Margaret in at all, so we couldn't have our kids together."

Mrs. Bachsmidt said: "I think personally, that it's an injustice to the families to keep children like this in an institution or in a hospital and not make avenues available to the family to become united again especially where it's saving money."

Dr. Kettrick said prolonged hospitalization results in a usurpation of parental authority:

> "When you are dealing with a hospital, you are dealing with a very strange environment, and it becomes difficult for the siblings and the parents and the whole family to maintain their level of authority over the child, other people begin to pick up that authority."

I. A SHORT LIST OF THE REASONS THAT HOME CARE IS MORE ADVANTAGEOUS FOR CHRONICALLY ILL CHILDREN

The experts interviewed in-depth in the course of producing this report were unanimous in their conclusion that home care was highly to be preferred over the

alternativeof keeping chronically ill children in a hospital or other institutions. Following is a list of some of the reasons given:

1. The Care at Home is Just as Good or Better than in a Hospital

Dr. Kettrick said, "The home can be just as safe and perhaps safer than it is in the hospital...our experience is that in terms of infection, in terms of nutrition, and in terms of the child's development, including cognitive development, the home is a better place than the hospital."

"We can provide the child with the same level of care at home that you can here in the hospital, and we would much rather do it at home and in Pennsylvania, by and large, we have had the financial resources to put together a package that would allow these kids to go home."

Ms. Weinstock said: "Children do better at home. Their families do better. The kids learn more, they seem to make more gains just being in a home environment. No matter how much we try to set up the hospital room, it is never like being at home."

Dr. Finnegan said he favors home care "because I feel that they (families) can actually do as well as far as their medical care and I think the children grow up to be better people."

Dr. Shabino said: "We have repeatedly demonstrated with our kids that nurturing is much better in the home than it is in the hospital setting."

Dr. Purdy put it this way: "I think that most families, given the opportunity, the education, the funding, and the backing, would probably do a much better job than the hospitals and that is not to say that the hospitals don't do a good job, but it is just better for the children with their families."

Dr. Culley said: "I think that up from the early part of the 20th Century until the last few years, health care has been so hospital-oriented...that we have unfortunately, equated hospital care with better care...we recognize that hospitals do not necessarily provide a better level of care for certain kinds of patients."

2. The Home Offers a Positive Healing Environment

The physicians interviewed described several cases of dramatic recovery or development in children who were not doing well in the hospital once they were sent home. Dr. Hartline described one such child and then stated that he does not agree with those who might suggest such development would ever have occurred in the hospital.

"I don't believe it. I think the major ingredient in that child's getting better was not just the coincidence of time, I think it was the difference in the developmental and psychological environment that can only be produced by the home."

3. Having the Child at Home Reduces Stress

"You got to the point", Mrs. Oaks said, "where you just couldn't stand to go to the hospital another day. The routine is just so demanding and overwhelming. It's just much easier having her home than in the hospital."

Mrs. Cannon said: "Having him here, I can spend all the time I want without worrying about going to the hospital, because when I do get home, I know that he is going to be at home. I like it a lot better having him at home."

Mrs. Russell said: "I feel that there is no better alternative for Daniel or for us. If Daniel were in the hospital, I would have to split my time between my two children."

"We're a family now," Mrs. Bachschmidt said, "I can get up in the morning and go in the bedroom and say good morning to him instead of having to wait until 6:00 o'clock in the evening to go see him. The girls get to pass by his room and say 'Hi, Robert', in the mornings. We get to eat dinner and play with Robert. I mean, we're a family now. We're not torn apart. Being torn apart can do a lot. It takes a big toll on a life. I think it's wonderful having him home. There's a big difference, big difference."

4. Home Care Aids a Child's Development

All of the parents interviewed said that their child had advanced developmentally after coming home. The word used most frequently to describe this progress was "dramatic."

The physicians interviewed agreed with the assessment. When asked to explain it, they said that the home is a very positive and therapeutic environment which aids the child's development.

Dr. Hartline said: "We have a lot of things over there, but there is nothing that you can do to make this institution into a home." He added that when home care has been arranged, "The child makes incredible adaptations into the home situation--both physiologically and more important developmentally."

Dr. Kettrick said that physicians have made the mistake of dismissing the potential of these children. We often say, "that this child does not have any developmental potential, let's not put resources into the child. We have been frighteningly wrong. We have had these children grow up and be cognitively advanced. And so, I don't think any of us are good enough to make those kinds of decisions." Dr. Kettrick described several cases, including one child who went on to be appointed to the National Scholastic Honor Society and another who became a very talented artist. He said home was important "not just in extending life, but in providing these children with a good quality life."

Dr. Purdy described another child named Eddy ,saying, "I really feel good because of the rapid strides that he made, that it had to be because of the home situation... there were many things that Eddy had to learn as a four and five year old that he normally would have learned as a two or three or five month old."

Dr. Shabino described several children who made dramatic advances after they were placed into the home setting. He said: "All of our kids surprise us because when they go home, we kind of wonder whether they will continue to make strides and each one of them has.

"I don't think that there is any question whatsoever and we duplicate this observation in every child that we have sent home..you can accelerate his development massively not only in terms of intellect, muscle and motor tone, but also their medical status. Most of these kids have some form of respiratory problem. The kids that we have sent home have shown marked improvement.

"This reflects the fact that there is more nurturing going on and their nutrition is better. They feel better. Who knows? We don't know the answer, but medically and developmentally, they just blossom."

Dr. Shabino concludes: "All of these children have made tremendous developmental gain since they have gone home and the reason for that is the normalcy of the home nurturing environment which we cannot duplicate here in the hospital setting no matter how much we try."

5. Home Care is Cost Effective

The issue of cost effectiveness is treated elsewhere in this section and in this report; however, it is a recurring theme among both family members and medical practitioners.

Dr. Hirsch said: "There is at least one better way to take care of these children, and that's at home whenever possible. If I was the head of an institution, I would sit down and just think about a child on a respirator, for example, that I could reduce costs by a factor of 10...I could keep the child at home, keep the family unit together, get the best possible medical care, and the best possible quality of life for the child."

The consensus is that cost effectiveness can be served in every case by bringing a child home, but that the decision should be dictated not by costs, but by what is best for the patient. The question should be: How can we insure the best quality of life for the child? The answer is universally: send them home and keep the family unit together.

No examples were found where home care costs were more than hospital care. Typically, home care costs only 1/4 of hospital care. But even hypothetically, if a case could be found in which home care costs were higher than institutional costs, the consensus among the experts was that it would be worth it because, in the words of Mrs. Fischer: "The home provides a better quality of life for the person, that's all there is to that."

6. At Home the Child Has More Freedom

Freedom is one of the most important words in the English language. It is, after all, the essence of America. As far as the families and medical experts were concerned, there was no excuse for depriving chronically ill children of their freedom.

The thought of a child being confined to a crib or to a tiny part of a hospital room boun by wires and tubes is especially abhorrent if the child can have freedom -- a chance to live at home with parents and siblings and be assured of requisite medical support. The consensus is that in most cases, a child, once medically stable, can be cared for as well or even better at home.

Mrs. Cannon said of her son: "He has got a lot more freedom here and he gets a lot more attention...he has freedom to do what he wants to do; he seems to be doing a lot better since he has been home."

Joe Miller, a patient in a hospital for several months because of an accident, talked about how he felt about being home:

> "You have that freedom again, and it gives you the motive and drive to want to do things like rehabilitation that you weren't doing in the hospital."

Stephen Brown, another long-term patient, described the big difference between home and hospital:

> "Well, I have a lot more freedom. I can meet my friends. I'm not alone. I am a lot more comfortable. I usually look forward to coming home."

Mrs. Reckeweg talked about what freedom and home care means to her child:

> "He's a different child. He's much, much, much happier. He's a normal child and he could never live as a normal child growing up in intensive care in a hospital, seeing the grueling things that he would see, and he did see. He absolutely loves his Big Wheel and once you see Jeff riding up and down on the sidewalk, riding his Big Wheel, and eating a Popsicle and the smile on his face, it would be impossible for me to justify him being kept in a hospital when he can have this life that he has at home."

Mrs. Clary said leaving the hospital was exciting. "To finally walk out that door and not have somebody telling you what you could and what you shouldn't do and just to let him go to sleep without the lights on, without the noises in the hospital without being awakened by other machines from other babies or having things done. It was really exciting to have him home, and just have him go and take a nap if he wanted to without any hassle."

7. Home Care Keeps Families Together: Children Want to be Home and Parents Want Them There

The strongest consensus in all the interviews was that parents prefer to have their children at home. It is not that they have any problems with the quality of care in the hospital (with few exceptions) rather, the parents register their strong desire to have their children with them as part of their family.

By every indication, the children themselves universally prefer to be at home, as well.

The evidence to support these two conclusions is scattered throughout this section. It exists in such depth that little purpose would be served by restating the obvious. The benefit of deinstitutionalizing children was summed up by Dr. Shabino with the observation that it seems a shame to waste the potential of children by keeping them locked and bound to institutions when, in fact, we can put them in a home care setting with their families where both the family and child want to be and enhance their recovery."

8. Home Care Provides Children With the Highest Quality of Life

There was a general consensus that home care provides chronically ill children with a higher quality of life than institutionalization. Mrs. Russell put this issue into perspective:

> "If the child's life is going to be re-endangered after that dramatic save they they had earlier in life by being at home or if they're going to have a poor quality of life living in an institution, I think that' s wrong. We have to be concerned about the quality of their life after the emergency is over."

Mrs. Russell said that there are so many things that you associate with your children that you cannot experience with your children in the hospital. She listed cuddling in bed on a Sunday morning, watching Dad shave, playing around in the cabinets and pulling everything out while Mom's cooking dinner or whatever. She said being able to do those things at home "makes it worth trying to bring him home regardless."

Mr. Russell added: "The hospital is no place for a child to grow up....trying to be a parent is just not right in the hospital. Even a good institution is not a good home."

J. SERVICE COORDINATION OR CASE MANAGEMENT IS VITALLY IMPORTANT TO THE TRANSFER OF CHRONICALLY ILL CHILDREN INTO HOME CARE SETTINGS

The term "case management" has taken on several different meanings, some of them completely contradictory. In one sense, the term is used to define any of the means by which insurance companies seek to lessen their liability under an insurance contract. Another meaning relates to assessment and decision as to the proper levels of care and appropriate settings in which individuals should receive such care. Yet another definition is a screening mechanism designed to limit the number of people who qualify for a certain benefit.

The final definition and the one embraced here relates to assessment, condition of discharge, and insuring that community resources are available to meet each child's specific needs.

Ms. Weinstock said, "We try to work things out so that every child has a case manager, one member of a team who oversees the care plan who has the primary responsibility for working with the family to insure what's best for the child."

The Visiting Nurse Society of New York used a team approach to case management. It is a team of professionals, nurses, physical therapists who help put together treatment plans in conjunction with the physician and who play the coordinating or case management role. The program has been enormously successful and since it is part of the agency which is supplying most of the needed services, costs are reduced. The same is true when such case management services are provided out of the hospital.

Dr. Shabino talked about the discharge team which provides this function at his institution. "The discharge team is made up of the child's physician, myself, by the social worker who functions as the case manager, and who is really a troubleshooter. It is made up of the nursing staff who put together the nursing program, occupational therapists, speech therapists, respiratory therapists and others."

Asked what the case manager does, he responded:

> "Well basically, you can guess from the fact that all these people are involved that it is sort of like coordinating a three ring circus. There is a tremendous amount that has to fall into place to make sure that the child can be cared for at home. Contingency plans must be put into place for all sorts of events."

The Individual Case Management (ICM) program of the AETNA Insurance Company combines many of the above elements. AETNA boasts more than 100 nurse reviewers and coordinators all across the nation who examine such cases and try to put together individualized plans which will allow the child to be taken care of at home with the requisite resources. The ICM program has a valuable side effect for AETNA. It saves money. AETNA representatives, Dr. Culley and Barabara Matus, RN, said that the program saved AETNA $36 million in 1985. Ms. Matus comments:

> "We like to say that everyone benefits from individual case management, and in fact, they do. The patient is a winner, because the patient is going to receive quality care and most often, a less restrictive and, more comfortable environment such as the home. There is also a decrease in stress on this patient. And he is able to be in an environment where he can be cared for perhaps part of the time by his loved ones. In addition to that, the family benefits because they too have been subjected to a considerable amount of stress and if we can ease that stress

in any way, it really helps them to become better parents or better caretakers of the person who is ill.

The physician is able to carry out his medical treatment plan in a setting that is agreeable to all and he is able to inject some cost containment into his practice. And, of course, our customers benefit because they are spending less money and have as the result, decreased premiums or rather premiums not being increased as rapidly."

K. PARENTS CAN BE TRAINED TO PROVIDE MANY MEDICAL AND NURSING PROCEDURES TO INSURE CONTINUED HOME CARE FOR THEIR CHILDREN

Families can be trained to perform medical and nursing procedures which will insure that their child can continue to live at home. Parents routinely are taught how to care for ventilator-dependent children. They are taught how to clean the child's breathing tube or trach, and how to suction the child if excess mucous develops in the child's throat which plugs up the airway. They are taught how to resusscitate a child who stops breathing.

It is a matter of getting the family comfortable with the technology, says Dr. Kettrick.

Ms. Jones told how she conquered her fear and finally learned to provide total care for her youngster, Stephen, who was hospitalized for a prolonged period of time after being hit by a car.

Ms. Jones said her training in the hospital took two weeks and that the training was done on dolls. She said she was taught how to flush an IV and to change bandages. "Well, I was nervous at first, my hand was shaking and the second time I really did it right and they were proud of me." She said that despite all the practice she was nervous about providing care for her son.

"He is a real human being. I could mess up a doll, but I could not mess up Stephen. I just calmed myself down, and I did it. I said to myself, I have got to put my mind into this in order to get my baby home. I just put my mind to it and relaxed and I did not shake any more."

L. FAMILIES WITH CHRONICALLY ILL CHILDREN LIVE WITH DANGEROUS LEVELS OF STRESS

There was a strong consensus among those interviewed that having a chronically ill child significantly increases the stress on the entire family. The pressure on parents is particularly acute, sometimes pushing them to the point of desperation.

Parents must live with the day to day knowledge that any moment the child's life may be in jeopardy and that unless the parents act quickly and properly, the child may die.

Parents must live with a degree of guilt. It is common for them to feel guilty about having a disabled child. Parents feel guilty when their children are kept in the hospital. Often they feel guilty when they must ask for help in order to manage the care and treatment of the child.

Parents often must forego their own hopes for higher education. They are locked into their current jobs in order to keep the benefits of insurance flowing to their dependents. Were they to change jobs, the insurance plan of their new employer might exclude coverage for the pre-existing health conditions of their child.

Parents with a chronically ill child must learn to live with huge debts, debts that will probably take them most of their lives to settle. They learn to haggle with insurers and suppliers in order to get what their child needs.

Single parents particularly have problems. The parent is in a Catch 22 situation of needing to work in order to keep insurance benefits flowing, but this would mean there would be no one at home with the child. Most single parents do not make enough money to employ a nurse to stay with the child while they work and to be with the child, watching over it while the parent sleeps.

Given all the above and the accumulated frustrations, families can be forgiven if their behavior is a little on the desperate side. The uneven nature of state benefits for chronically ill children puts families in the position of having to move from state to state in order to try to find some help for their child. One family, the Bachschmidts moved three times in the first two years of their child's life.

Following are quotations from the interviews which amplify these and other points.

Dr. Shabino made the point that having a chronically ill child at home requires a total commitment on the family's part. "And these are special families. Their total lives revolve around the care of these children and I think that we as a society ought to be very supportive of their efforts and try to minimize the roadblocks that are thrown in front of them."

Mrs. Mature was asked what percent of her time was spent taking care of her son, Eddie. She responded, "Almost all of it."

Mrs. Reckeweg added: "Our life does revolve around Jeff. We try to make it a very normal life but it does revolve around Jeff...As a parent, I feel that I am Jeffrey's strongest advocate; that there is nobody who loves Jeffrey like I do, because I am his mom and that is why I put so much fight into getting him home and keeping him home."

Ms. Joni Knapper, a nurse with UpJohn HealthCare Services, provides this perspective:

> "He (the child, Ivory) can be difficult to take care of, but the thing that we always remember with Ivory and children like him is that at any moment he could be in a life threatening situation. Of course, we have to be ready to respond to that life threatening situation. He is very rewarding to work with as are all of these children. They give so much love in return and there is such significant progress with these children even though it is difficult at times."

Mrs. Barcliff said: "I wanted her home so bad, but looking back, now I was tired. I lost weight. Things hit me real hard. I had a very short fuse. Amy would ask for her breakfast and I'd kind of throw a bowl of cereal at her...there is no way a single person can do it 24-hours a day around the clock."

Mrs. Russell said: "It is very difficult living with the responsibility. We live 20 minutes from the hospital...And he has got five minutes if a problem develops. You can't wait for the ambulance. You have to do something. And when you face your child laying there needing something and if you can't do it, his life is over with, that's a huge responsibility. But I would rather take that risk of something happening than to have his life be one in the hospital."

Mr. Russell added this penetrating insight:

> "To bring a child like Daniel home is a tremendous strain on your time and energy. It's an around-the-clock responsibility that's completely demanding all the time. And on top of his medical needs and those demands, you also have to perform all the other functions of a hospital. You are the billing department and the business department. You're following up on the insurance that didn't pay.
>
> "You're the inventory control. You're ordering the supplies and being sure that you have everything that you need. And all that takes all your time and energy and that's fine and dandy. But when you turn around and find that you forget to do some normal human thing because you were busy doing this or, Lord forbid, that forget something to be done and there's a problem. It's extremely stressful on the family structure.
>
> "You know, you're pressed to the limit as it is and your ability to absorb a minor misstep is very slight."

Mr. Buckholtz said: "Emotional burdens have been rough. Especially earlier on when Brandon would have a respiratory and/or cardiac arrest at any given time. There were times when he'd have rapid fire respiratory arrest and he got Medivaced back to John Hopkins Hospital because there was no way that we could take care of him by ourselves on a full-time basis. So when that happened, either Karen or I would end up staying up with him during those times. Somebody was awake with him at all times. And, it was extremely rough doing that."

Mrs. Buckholtz developed severe anemia and bleeding ulcers and herself was hospitalized under the pressure of trying to care for young Brandon. She said:

> "Brenda had to learn to take second place, and that's hard, especially for a child who has chronic lung problems as well. She had, we had to make sacrifices. My husband had to realize he was going to have to stay at his job for yet another year and now he's going to have to put off school for yet another year. And I eventually had to leave my job because I just, I ended up so sick, I ended up in the hospital, so I had to stop work."

In summary, family members agreed that there are severe pressures associated with having a chronically ill child. The stress affects all members of the family. It affects the parents in their employment and in all aspects of their lives. The stress is far worse when the child is institutionalized. Some parents report they have been driven to the point of wanting to break their children out likening the hospital to a jail. The pressures of caring for the child at home are still considerable, but much less than having the child in the hospital. On balance, families can deal with the stress with some support and they have a strong desire to have their children at home with them. Mrs. Oaks speaks for all when she said of her baby: "We were just thrilled to death to be able to bring her home."

M. HAVING A CHRONICALLY ILL CHILD GENERALLY BRINGS A HUSBAND AND WIFE CLOSER TOGETHER

What effect does the presence of a chronically ill child have on a marriage? It is a close question. The majority of those interviewed said that it brings a husband and wife closer together. However, a fairly large minority were of the opinion that a severely ill child introduces an intolerable amount of stress which often has the effect of breaking marriages apart. The question is further clouded by the fact that half of all U. S. marriages end in divorce. The reasons for such divorces are many, varied and complex. It is quite difficult, in such circumstances, to identify the birth of a severely handicapped child as the proximate cause of the marriage dissolution.

The best guess seems to be that the birth of a child who is dependent brings husband and wife together, creating a strong need for them to work together to insure the survival of their offspring. There is no more powerful influence than this. Whether it leads to a long term strengthening or dissolution has a great deal to do with what kind of a marriage it was to begin with. Strong marriages seem to benefit while weaker ones may tend to disintegrate.

Dr. Shabino had these thoughts. He said, "having a chronically ill child renders the marriage relationship abnormal. The relationship with the rest of the family is abnormal because of having someone in the hospital. This interrupts the family schedule. So it is disruptive to other children at home and disruptive to the relationship between mom and dad."

Mrs. Russell said: "I think it's been a real stress, but I think that in a lot of ways it's brought us closer together because in so many ways, it has been us against the world. We knew each other for a long time before we had kids and I'm glad of that because it's real easy to turn against each other instead of turning to each other."

Mr. Russell added: "It is really intensive stress and I think in some sense, it's limited the amount to which we can be creative in our relationship because in a kind of energy management program where we have just barely enough to squeak by. And so you don't rock the boat in a way that you might if you had available energy. So in some sense it makes you more conservative."

Mr. Oaks had a similar notion: "It has been quite a strain on us, a strain on the whole family but it has also brought us a lot -- brought the whole family closer together."

Mrs. Shannon said that having a chronically ill child had both a positive and a negative effect on their marriage. "I think there is an incredible strain without question. What ends up happening is, it bring two people, it brings the whole family together. It brought my husband and I closer, but then it's also brought us farther apart. There's an incredible amount of work that has to be done. Erin not only has a medical problem, but along with that you have to make sure that she's going to be allowed to go to school and have full opportunity to participate in society."

N. HAVING AN INFIRM BROTHER OR SISTER CAN HAVE PROFOUND EFFECTS ON THE OTHER SIBLINGS

Most of the families interviewed who were dealing with a chronically ill child had other children. Most of the time these children did not suffer from the same kinds of health care problems. There were, however, notable exceptions to this rule.

One woman in New Jersey, for example, is presently caring for three ventilator-dependent children in her household at the same time. One child is burden enough. Two would be difficult to handle, but three is beyond difficult.

Another exception involves twins. A high percentage of twins are born premature with relatively low body weights. In such cases, there is a good chance that if one premie twin is born with problems, the other will also have problems of one degree or another.

Disregarding the exceptions, how do children react when a chronically ill child is born into a family? The consensus among those interviewed is that it accelerates the child's normal feeling of rejection. The attention that he/she enjoyed has now been shifted to the newest member of the family. This is even more true when the newcomer has major health problems.

Under these circumstances, it is not unusual for the older child to withdraw, to become depressed or feel neglected. Older children may be pawned off on friends or relatives because the attention of their parents is elsewhere. They sometimes fake illness of their own. They may feel that somehow they are responsible for the illness of the new sibling. In other cases, the older children instinctively understand the situation; depending on their ages, they pitch in and are supportive.

Having a chronically ill sibling can mean that all of the family's income as well as its time and energy is directed somewhere else. This may jeopardize the older child's chances of going to college or otherwise deprive the elder child of opportunity.

There is an endless list of possibilities and responsible parents work very hard at not neglecting other children in their great concern for their newest and ill infant.

Following are some quotations from the interviews. Mrs. Russell talked about the fact that her son, Daniel, was in the intensive care unit and in isolation. The hospital would only allow one parent at a time with the child. This made it impossible for the entire family to be together on special occasions such as Christmas and birthdays. Asked how they handled the situation she said:

> "We traded off. One of us would stay with Margaret while the other went to the hospital, and then we'd trade off. One of us would bundle Margaret up and carry her over and we'd meet in the lobby and trade off so that Daniel wasn't left alone either."

Mrs. Russell went on to say that when he was finally discharged to their home, it helped Daniel a great deal to be around his sister. "Being able to be with a sibling, especially someone his age, is the kind of motivation and the kind of therapy that you could not buy in the hospital."

"They get along great," she continued. "They're really close. They hug each other and they fight just like normal kids do, but they also protect each other.

"Margaret is very sensitive about Daniel. About six months ago, Daniel's airway obstructed at home and it was very upsetting for us because he almost died right here while we were trying to get the ambulance here and get him to the hospital...Margaret has to be a part of that too. And I think she understands it.

"She plays that she takes her bears to the hospital and that their trach is broken and they have to have an IV in. We had to get her her own suction equipment so that she could play with her dolly that way, so that we could keep her away from Daniel because she wanted to help take care of him, too."

Mrs. Reckeweg offered this perspective: "The first nine months or so I lived at the hospital. The only time I left was to come home every other day to get clothes and then go back to the hospital. Then I realized the damage and the harm that I was doing to our other son. And I came to the conclusion that I could not spend every waking moment with Jeff, that I was going to have to spend some time with Andy, our other son."

When asked about how having Jeff home has affected Andy, she responded:

> "It has actually been much, much better for Andy. He's been a much happier child since Jeff's been home, basically, because I'm home with him full time whereas when Jeff was in the hospital, I was with Jeff almost all the time. It's real hard when you have two children to decide which one that you're going to be with and I was very torn because I was sort of playing favorites towards Jeff. That is not what I intended but sort of what turned out."

D. HAVING A CHRONICALLY ILL CHILD STRAINS FRIENDSHIPS

The support of friends is generally both welcome and valuable in times of crisis. The interviewers, therefore, asked family members caring for a chronically ill child about the support they received from their friends.

The consensus of opinion is that friends continue to provide support, but that it is very difficult to sustain friendships because the family is going through the crisis does not have the time or the energy needed to nurture and keep the friendship alive.

Typically, families going through a crisis with a technology-dependent child will seek out support groups of families with similar problems. This allows the parties to communicate about common problems, to provide each other encouragement, support and good advice drawn from relevant experience.

Mrs. Russell provided this perspective:

> "We have had to establish priorities. Our priorities have been our kids, our marriage and our job, whoever has the job and getting Scott (her husband) through his degree that he was in the middle of when all of this happened to us.
>
> "We dropped the garden. We stopped working on the house. We stopped doing housework. We got to the point where we said that we can't sustain our friendships. If we don't have any time to ourselves or any privacy to ourselves, we can't afford to go out with our friends.
>
> "And your friends have to go on. And I know they love us and they care for us, but their lives go on even though our lives are different. It is very diffcult to understand. It is a very unusual situation and it takes so much energy to explain. It is so complicated even to explain his condition. I have talked to other mothers through Children's Hospital and they all say the same thing. When someone asks you how your child is doing, you don't know what to say because there are so many different ways of looking at it. After a while you stop trying. You just say: Fine. Everything is okay right now."

Mr. Russell added these thoughts: "You can't really share something this intense and as complicated...so there's only a limited extent to which we're able to get support from friends.

"We really don't want to stress our friendships by making this the only thing we relate to our friends about and at the same time, our energy for maintaining friendships has gone very low."

P. THE HAPPIEST MOMENT FOR FAMILIES: BRINGING THE CHILD HOME

There was almost unanimity of opinion among the families interviewed as to the best part or happiest moments associated with the care of their technology dependent or disabled child. They all agreed that the best of times was when they were finally permitted to take their child out of the hospital. Most of them answered the question of what had been the best time for their families since their child's birth by simply saying, "Bringing him home."

Q. MOST DIFFICULT MOMENTS INVOLVE HEALTH CARE CRISIS OF THE CHILD AND REFUSAL OF THIRD PARTIES TO PAY FOR CARE

In the course of the interviews, parents were asked, "what is the most difficult part of having a technology dependent child"? The general consensus was that it involved a crisis facing the child. Typical of the responses was that of Mrs. Young, who answered:

"When it first happened, not knowing from day to day if he was going to make it through."

Mrs. Mature answered in almost identical language:

"When he gets real sick and we do not think that he is going to make it."

Mrs. Oaks said the worst time was the "first week with all the surgeries, being told that there were things wrong with your baby, and sitting in the waiting room not knowing what the results will be".

Mrs. Reckeweg, like other mothers, had to learn to live with frequent episodes where her child, Jeffrey, just stops breathing. Her particular worst moment, she said, was when Jeffrey went into respiratory and cardiac arrest. "We worked on him for half an hour; he was unconscious for 45 minutes. And we didn't know if we were going to be able to bring Jeffrey back; whether he was going to be severely brain damaged or what was going to happen."

Mrs. Clary said the worst time was "having to leave him every night at the hospital".

Mrs. Russell mentioned the same kinds of experiences, but said that even worse were the frustrating moments when they learned that insurance or Medicaid or some other entity would not pay for Danny's care as had been promised.

This same point was extended by several parents who noted that there are so many barriers placed to keep them from receiving the home care they need. The failure of government or insurance to provide financial support ranked very high on everyone's list of worst moments.

B. REHOSPITALIZATION HAS NEGATIVE EFFECTS ON CHILDREN

Both medical experts and parents were in strong agreement that children, even very young children have a pretty good understanding of the difference between being home and in the hospital. The child's preference almost universally is to be at home with the maximum degree of freedom that his or her disability will allow. Rehospitalization generally means the child will become depressed.

Ms. Weinstock of Childrens' Hospital put it this way:

"We have examples of children who when they are rehospitalized with a recurrent problem will regress in their development, become withdrawn and depressed. And once these children go home again, we have seen them return to normal, eating, developing and interacting with people".

Ms. Lierman, also of Childrens' Hospital, described a little boy named Andrew whose reaction to the hospital was to keep his eyes tightly shut. She said that the event was so traumatic that even after he returned home, he would not look at anyone. "He would keep his eyes closed all the time, and it would take about a week of him feeling safe and secure before he would finally start to open his eyes."

Dr. Finnegan was asked what would be the effect of rehospitalizing his patient, young Danny Russel. He responded:

"It would be disasterous, especially at this point for Danny now that he has become attached to the home. It would create a depressed child who, in fact, may even withdraw from the world."

5. THE NEED FOR RESPITE CARE

There was a strong consensus among those interviewed about the need for respite care. What is respite? It is an interval of rest, relief from the source of daily responsibilities in caring for an ill or disabled person at home.

The caregivers who were interviewed all talked about the enormous stress placed upon them which often pushed them to the point of burnout. Caregivers unanimously testified that with relief in the form of a few hours or days away, they were refreshed and once again able to carry the many burdens associated with care of a chronically disabled child.

Ms. Liermon of Childrens'Hospital in Washington, DC, made the point that for want of respite care, children wind up being placed in hospitals and nursing homes.

Dr. Kattrick pointed out that Childrens' Hospital in Philadelphia offers respite care which allows families to admit their children for a couple of days, but he adds, families "prefer to get their respite care at home. They will either take their children with them on their holidays or they will arrange for nurses to care for them at home when they go off on holidays."

Dr. Finnegan agreed, saying, "One of the biggest things that you can provide with your support personnel is respite care. There are many ways that this support can come. It may not cost anything. It may be as simple as having a network of volunteers who can help each other out."

For the Oaks family, the pressure of watching a child 24 hours a day would be unbearable. Having a nurse in the home to watch the child at night time allows the family the most important form of respite - a good night's sleep. Mrs. Oaks talked about the importance of this. "There is no way for more than one or two days in a row I can handle the responsibility 24 hours around the clock. One night without sleep, getting up and watching her all night, and I am gone."

Mrs. Russell said that her family has nursing 12 hours a day, eight hours a day while the child and the family sleeps. "There is no way that we could safely take care of Daniel at home without that." The other four hours of nursing care, she said, provides the family with respite, allows them time to go shopping, run errands, pay the bills, and perhaps even have a few minutes alone.

Mrs. Fischer agrees, "We just need a break from this day to day, year after year responsibility of having them constantly in the other room."

Stephen Brown's mother, Diane Fleming, talked about another form of respite: nurses with a van equipped with a lift who volunteer to transport and care for Stephen when he goes to movies, concerts or baseball games. The point is that the children themselves, particularly as they grow older, are in need of a break. They welcome the opportunity to go on an outing, but their disability sometimes means that they must be dependent upon others to do so.

T. THE NEED FOR EDUCATION OF CHILDREN AT HOME

Another important point made by many parents is the need to work with and help educate children while they are at home. Many of these fragile children have spent one or more of their formative years in the hospital. As could be expected, their development was therefore hindered. This makes it all the more important that family members work with the children, giving them every possible opportunity to grow and develop both mentally and physically.

Family members expressed the importance of exposing the child to new experiences, talking to the child while dressing or feeding them and/or playing with the child. It was suggested that some families became over-protective of their child out of fear, thus inhibiting the child's growth and development. A proper balance between freedom and supervision must be reached.

Once the children reach school age, family members recommend that every effort be made to send them to public schools where they can be treated as much as possible like other children. Medical experts, such as Dr. Kettrick, believe strongly that society must put more money "into developmental and educational care of children who had chronic diseases."

Dr. Shabino said that his community was fortunate enough to have the school district provide education in the home as well as in the school setting for these special children.

Katie Beckett and Erin Shannon both attend public schools. Classmates have been educated as to their special problems, and are generally very accepting of their colleagues. Classmates sometimes assist in the care of fragile children. In some cases, either the parent or a nurse must accompany the child to school every day. Someone needs to be on hand in case there is an emergency. As Karen Shannon notes:

> "Not only are we Erin's nurse while we are there, but we are also a helper. We're also an aide. So we are an extra pair of hands for the teacher, which has proven to be very, very beneficial."

Clearly, there is a consensus that if these special children are ever to reach their full potential, they must have education first from their parents in their own homes and later from their parents and the public school system.

U. THE NEED TO EDUCATE MEDICAL/NURSING PERSONNEL

There was a consensus of those interviewed as to the need to educate physicians and nurses as to the special needs of technology dependent children. Some of those interviewed suggested that this education should be extended to all members of the caring professions from social workers to physicians. It was suggested that these fragile children need a wide array of health care and supportive services. Those who provide the care must be educated as to the special needs of this patient population.

For example, Dr. Kettrick of Childrens' Hospital in Philadelphia was asked: How do we educate the health care community? He responded:

> "That is difficult. We struggle with that in Maternal and Child Health. But I guess I would say, set the money aside to have--there are established mechanisms for educating people, health care professionals and families. We just need to use the existing channels. And education materials can be disseminated through the medical schools, through the sub-speciality training programs in pediatrics, and in all of the various pediatric sub-specialities, and they can be passed through the various state agencies that take care of, or facilitate the care of children with chronic diseases. To me the mechanisms for dissemination are there. The channels are there. What we have not done is to put the information in the hopper in the beginning. And the only area where we assume that good education is available, and I don't believe that it is available, is in the medical schools. The basic curriculum for medical students does not emphasize chronic disease, does not emphasize the fact that much of what these individuals will be eventually asked to provide care for, is the chronic diseased patient population. And we do need good education programs in the medical schools. They do not exist."

V. THE NEED TO EDUCATE THE PUBLIC AND THE CONGRESS

There was unanimity of opinion among those interviewed as to the importance of educating the public to the plight of technology dependent children and the pressures placed upon their families.

It was a consensus of opinion that the problem of large numbers of dependent infants was so new as to have escaped the notice of the public generally and of the Congress in particular.

Those who were interviewed expressed the opinion that if the public just understood the current dilemma, they would exert political pressure on their elected representatives to institute reforms. It is the general feeling among the group that this issue is one of common sense. It has only to be explained in order to win public support.

The group decried the lack of stories on television and in the printed press. Increased media attention, it is believed, will lead to rapid reform.

The lack of education also extended to families who might have a child with birth defects or other problems but not know how to go about obtaining the care they need.

Dr. Finnegan said that people need to know there is an alternative to keeping their fragile children in a hospital. He said that recognition of this fact was slowly coming, but that people for the most part do not see home care as a viable alternative. "To put it simply, yes, there is. Public education is needed."

Mrs. Bachschmidt said, "I think that people in our situation are misinformed. Unless they have someone to tell them certain avenues to take, a lot of kids go to nursing homes because no one told them that they could take this child home. No one told them that there was a way to fight the system."

Dr. Kettrick spoke of the importance of educating the Congress. "I think we have to target those people. There are a lot of people after them so they...retreat into their shells. But I think we have to go after them and educate them on a personal level."

W. THE NEED FOR PEDIATRIC HOSPICE

There was a consensus among those interviewed that pediatric hospice programs should be created or expanded. Hospice involves a coordinated program of palliative and supportive services for a terminally ill person and his or her family. In hospice care, pain and symptom control is given top priority. Every effort is made to help the patients live life to its fullest. Hospice services usually are offered through a physician-directed interdisciplinary team. Following the person's death, bereavement care and follow up services are provided to the family to help them through the crisis.

Those interviewed pointed out that there are hospice benefits available to the elderly under Medicare, but that there is no parallel hospice program for children.

X. HOME CARE IS SIGNIFICANTLY MORE COST EFFECTIVE THAN COMPARABLE HOSPITAL CARE

According to all of those interviewed, in their experience, home care services have proven less costly than comparable care in a hospital. Everyone agreed, however, that cost effectiveness should not be the central criterion which determines whether or not a child is returned to his or her family. The primary determinant should be the best interest of the child. By either standard, home care was the clear winner with families.

Dr. Shabino said, "In our experience and in everyone's experience, it ends up being cheaper to keep these kids at home."

Dr. Hartline said: "We find that moving the child or the patient into the home costs about 20%, 25%, 33% of maybe even 40% of what it would cost to keep the same child in the hospital environment. If we could really be sure that the only patients that were moved were the ones who would stay in the hospital anyhow, then the money that you would save would be obvious."

Dr. Hirsch said, "Not only is it so much better for the family to able to take care of the child at home with assistance, it is also exceedingly more cost effective, sometimes by a factor of ten."

Dr. Kettrick from Childrens' Hospital in Philadelphia said that "care can be provided in the home at a cost of 1/4 to 1/3 of what the hospital costs would be." He added that, "the home can be just as safe and perhaps safer than the hospital."

Among those interviewed, the average cost of care at home, was 1/4 of the cost of comparable care in the hospital. The highest cost relative to hospital care was reported by Mrs. Fischer whose daughter's care averages about $74,000 or roughly half of the cost of comparable hospital costs. On the low end of the spectrum, Mrs. Miller reported that the cost of caring for her child at home was 1/18 of the cost of $18,000 monthly hospital costs.

Mrs. Reckeweg reported that home care costs run about $14,000 a month or less than 1/4 of the $60,000 monthly costs of comparable stay in a hospital.

Ms. Lierman from Childrens' Hospital reported that in general, home care costs were 1/4 that of hospital care for the same child. Mrs. Barclift's child ran up a $1 million hospital bill in the first 18 months of his life, and is cared for at home for 1/4 of the monthly costs.

Mrs. Russell reports that Danny costs $60,000 a year to care for at home, while hospital costs range from $300,000 to $400,000. In their experience home care costs less than 1/5 the cost of a comparable hospital stay.

As is noted above, there is a clear consensus on the issue of cost effectiveness among the families and medical professionals interviewed. Their actual experience which may be described as anecdotal, is also well buttressed by objective studies which are reported in another section of this report.

V. DANGERS OF HOME CARE

Family members and medical professionals both discussed a number of dangers associated with pediatric home care. The first and foremost of these was the ability to respond in a medical emergency.

"There is nothing to guarantee that the children will not have some medical emergency at home", Dr. Shabino said, "just as they might here in the hospital. There is a risk, but what we are judging here is the risk of the disaster happening at home, which we take every effort to minimize, versus what we see as a tremendous benefit of having the kids at home. And that far outweighs the risk of it."

Mrs. Russell said: "Everybody is optimistic about home care, and it's possible but I think it is foolish to try to tell parents that they ought to do this on their own. I think that's dangerous to the children." Mrs. Russell was concerned that the states and third party payors will simply discharge the chronically ill children from the hospital into the home and custody of the parents without providing the parents with the necessary support they need.

Dr. Purdy agreed saying: "We may see a push to get all of these children home. I think that is going to be a problem unless we really train the parents and screen the children and really make sure that this is the right program for them."

Several parents and medical professionals stressed the importance of being able to admit the child to the hospital when this was necessary. Both groups were wary of a policy which took on overtones of "dumping" with the primary goal of saving money.

All parties agree that the individual needs of the patient must be evaluated on a day to day basis and efforts must be made to provide care requisite to those needs in the least restrictive environment.

Another concern expressed by several families was the problem of untrained or unprofessional nurses, aides, or therapists. Both the Buckholtz family and the Shannon family talked about unhappy experiences they have had with caregivers who either did not keep appointments or who were not adequately trained to do their job. There was at least one report of a family bringing suit against an aide for unprofessional conduct which they say led to the death of their child.

A related point is that the costs of obtaining nursing care in the home through a licensed agency is quite expensive. It is only a fraction of the cost of a comparable stay in a hospital or a nursing home, but it is still expensive. Home health agencies which participate in the Medicare program, for example, must meet a long list of rigid criteria. The fact that the agency is responsible for the training and the supervision of its workers is important, as it relates to quality of care. But such training and supervision also costs money. As a result, some families have obtained the services of "independent contractors" who have no affiliation with a home health agency. They do so in hopes of saving money. Unfortunately, they can be assuming unwanted risks if the individuals in question have inadequate supervision or training.

Unfortunately, too, some states also contract with individual providers as a way to preserve state funds. States themselves hire such independent contractors because this faction spares them the responsibility of paying unemployment and other benefits. Moreover, if an individual is ever sued and poor care is alleged, the state can try to walk away from liability by saying the person was not a state employee, but an independent contractor. Some states have gone so far as to hire such people and maintain that the infirm client is the employer even though the state pays all the bills directly from the state treasury.

The problem of independent contractors clearly is one which must be addressed. The need for special minimum training programs for nursing personnel who work with chronically ill children is also apparent.

Z. ADVICE TO OTHER FAMILIES: FIGHT FOR HOME CARE

During the course of the interviews, families with chronically ill or severely disabled children were asked what advice they would have for others similarly situated. The responses were unanimous: fight for home care and bring the child home from the hospital.

Mrs. Jones said: "If the child can come home from the hospital, I would tell them, get home care."

Mrs. Reckeweg said she would advise families "to fight for home care 100% because it is very, very wellworth the effort; it is worth every ounce of energy that you put into these kids, to see them grow; to see them develop to their fullest potential."

Mrs. Mature said: "It is real tough at first and to really stick with it, things do work out and it becomes easier as time goes on. Just stand up for what they think is right for their child and do not let anyone change it."

Mrs. Oaks said her advice would be: "Not to give up and just to keep on getting through the rough stuff because it gets better. There is light at the end of the tunnel, but you could not have told me that the first month. The first week, your whole world is coming to an end. The first week, I never imagined getting to the point where she'd be home and I'd be able to care for her. And it is a great feeling to know that we can take care of her and she's ours again."

Mrs. and Mrs. Bachschmidt answered: "Don't lose faith in yourself or in the good Lord above. Fight! Just don't take no for an answer. Knock on every door...If someone says no, find out why. If it doesn't seem correct, go higher and higher. I spent eight hours a day on the phone talking to people and sending out thousands of letters.:

Mrs. Buckholtz said: "You cannot be a voice on the telephone or a signature on a letter. It just doesn't work. You've got to personalize your attempt to get home care for your child. We had to see people face to face and deal with them. Without a letter of medical necessity from a resourceful physician, you can't do anything. You've got to have that. You've got to get the powers that be together to decide that it is better to have the child at home, more cost effective to have the child at home than it is to keep the child in the hospital."

Dr. Kettrick joined in the above, but added the advice that parents should "make contacts with legislators on a state level that will effect change."

VI. THE FUNDING ROADBLOCK

At a June, 1985 hearing before the Senate Committee on Labor and Human Resources, Committee Chairman Orrin Hatch (R-UT) asked the mothers of three chronically ill children what the single greatest obstacle was to bringing their children home and caring for them in that setting. All three - mothers from three different states - gave the same answer: funding. All three told the Senate Committee that the need for legislative action in this sphere was paramount. Senator Hatch concluded, "It is apparent that we do need to bring our legislative enactments into the modern world, into the high-tech world, and to help these kids."

The story told by these parents was not new. Ranking minority member (now Chairman) Senator Edward Kennedy (D-MA) acknowledged that "[It] has been told to the Congress for years...You have reminded us again and, quite frankly, you ought to keep speaking of this issue until we are going to do something about it." What, then, is the problem, and why hasn't something been done about it? The only discernable explanation for this failure of public policy appears to be ignorance of the dimensions of the problem and the benefits arising out of its resolution. Simply, that third party payors, public and private, have failed to adjust their reimbursement mechanisms sufficiently to take the home care option into account.

In-hospital care is extraordinarily expensive. Costs of $1,000 per day or more are not unusual in the care and treatment of ventilator-dependent and other handicapped children. Private insurance is quickly exhausted, often during the child's initial stay in the hospital.

Then comes the harshest reality. Just when medical science has made it possible to bring many chronically ill children home to their families, the families discover that neither their private health insurance nor any government-funded medical aid covers the cost of home care services for them, despite the fact that those services may be available for just a fraction of the cost of in-hospital care.

The story of Katie Beckett is illustrative of how the payor's failure (in this case Medicaid) to keep pace with advances in medical science can literally force parents to keep their children in hospitals rather than bring them home, even though home care is less expensive and even though home care promises a potential for greater recovery in many cases.

Katie Beckett was born on March 9, 1978, in Cedar Rapids, Iowa. Although she was premature and weighed only two pounds, three ounces at birth, Katie initially had few medical problems. After forty-eight hours, she no longer needed an oxygen hood, and her development was such that she was released to go home on May 6. She was a "normal" baby as far as anyone could see. However, by September 1, Katie was back in the hospital, suffering, it was later discovered, from viral encephalitis. On September 2, Katie aspirated, and severe respiratory distress complicated an already serious illness.

Katie made significant, even miraculous, progress in overcoming the horrifying after-effects of viral encephalitis. Finally, doctors informed the Becketts that they could bring Katie home. Their euphoria turned to sadness and bitter disappointment, though, when they realized that by bringing Katie back to the family, they cut themselves off from the Medicaid benefits necessary to pay for Katie's health care.

Under Medicaid regulations, when a member of a family is separated from the family for a period of time, the individual's eligibility for Supplemental Security Income (SSI) assistance is considered on the basis of his or her individual circumstances with-

out reference to family income or resources. Katie spent a year and a half in the hospital fighting against her disease; thus, she became eligible for government assistance to pay for her hospital costs of approximately $12,000 per month. However, when Katie was ready to come home, she was once again, for purposes of SSI eligibility, deemed to have access to her family's income. Even though the cost of caring for Katie at home was $2,000 per month - one-sixth what it cost to keep her in the hospital - it was a cost the government would not bear. Katie's parents either had to find some way to afford $24,000 a year in home health care, or they had to keep their daughter in the hospital.

The regulations which hampered Katie's return to her family were called "hidebound" by President Reagan, and Mr. and Mrs. Beckett waged a long and difficult war to overcome them. Initially, they met with failure and disappointment everywhere they turned for help. They had exhausted all lifetime major medical coverage on their Blue Cross/Blue Shield plan. They were faced with the prospect of dire financial straits, including bankruptcy, since the nature of Katie's illness would inevitably require her to return to the hospital setting for treatment. As Mrs. Beckett told a Senate Committee in 1983, "A child with a wonderful potential for a full life at the age of three years was left with no health insurance coverage. This shows the giant gap between governmental and private insurance coverage that is left because legislation has not kept up with major medical technology."

The Becketts sought help from the Bureau of Medical Social Services after a caseworker at the social security office explained that "his hands were tied" and "rules were rules." The Bureau explained to the Becketts that they could apply for an "exception to policy," but no one from Iowa had ever received one. Katie's parents tried to obtain private funding, too, but each time, they met with a negative response. Crippled Children, the Heart Fund, and the March of Dimes all told the Becketts that apart from loaning equipment, they could be of no help because Katie did not fit into their guidelines for grants to aid research and education.

Finally, in June, 1981, Mr. and Mrs. Beckett sought the help of their Congressman, Tom Tauke. Tauke's office gave support to their application for an exception to policy, since the pressures of budget cuts made it unlikely that a private bill would alter the prohibitive regulations. The process took months. In contact after contact with the appropriate state agencies, the Becketts were forced to relive the brushes with death they had encountered during Katie's long and difficult convalescence. The frustration and anxiety levels endured by the Becketts ran high.

Congressman Tauke sent the Becketts' case to then-Secretary Richard Schweiker of the Department of Health and Human Services, but on November 4, 1981, he received a letter rejecting the request for an exception to policy. Tauke, undaunted, turned to Vice President Bush. Through his, President Reagan's, and Secretary Schweiker's intervention, Katie was able to return home. In the ten months preceding her December, 1981 hospital discharge, Medicaid paid hospital claims averaging $13,100 per month. In the thirteen months after she went home, Medicaid paid an average of just over $3,500 per month. This figure includes $21,000 for five inpatient hospital stays. During her actual time at home, Katie's Medicaid bills were about $2,000 per month.

The Katie Beckett case resulted in the passage of Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA), effective October 1, 1982. Under the provision, known as the "Katie Beckett Waiver," states were given the option of making SSI payments to disabled children 18 years of age or younger cared for at home. The specifics of the provision are set forth later in this report.

As for Katie herself, she improved remarkably. Serious illnesses became less and less frequent after the initial discharge. She began preschool, where peer pressure worked for her in a very positive way. She developed at a rate far beyond anyone's previous expectations. While it was once thought that Katie would have to sign to communicate, that is no longer the case. In fact, her exposure to other children in a learning situation helped her to the point where, by her fifth birthday, her vocabulary ability tested out at an average of seven years and her level of understanding at that of a six-year-old.

Katie Beckett's success story is the product of many coordinated efforts. Speech therapists, physical therapists, respiratory therapists, school officials, psychologists, sociologists, and suppliers were all committed to helping her grow. Katie, in turn, demonstrated that technology dependent children can and should do very normal growing, particularly when they have the opportunity to do so in the environment of home and family. In short, they should be allowed the opportunities this society seeks to offer any human being.

Other children have shown similar successes; the stories of a few of them appear throughout this report. There is a clear message coming from these stories, and the message is that children have an amazing resiliency to serious medical conditions when they are in the supportive environment of home and family. In and of itself, this message translates into a mandate for a greater allocation of funds for the home care alternative. But there is another part of the message, too. That is that in case after case, home care is less costly.

Yet the Beckett's and other families like them have found that federal programs to provide economic assistance often hinder rather than help them in their efforts to bring a chronically ill child home. The problem is twofold. First, there has been a failure to commit a sufficient proportion of the nation's health care dollar to pediatric home care. Second, the money that is available to care for chronically ill children and for those who have been disabled through accidents is not dispensed through a single, coordinated program that would unify eligibility criteria and help minimize the number of uncovered children and cases. Ultimately, the funding problem demands a comprehensive and organized effort. In the meantime, families must seek out limited funds from any of a number of federal or federal/state programs for which they may or may not qualify, depending on the program, their child's disability, their income, and even where they live.

There are four major sources of government funds for pediatric home care: (1) Medicaid (Title XIX of the Social Security Act); (2) the Maternal and Child Health Services Block Grant (Title V); (3) Block Grants to States for Social Services (Title XX); and (4) the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS). Each of these sources has a different focus. In some instances, the programs may overlap in terms of the children covered. However, in many more instances, there are huge gaps between the programs, with the result that overwhelming numbers of chronically ill children fail to get any public assistance at all.

1. Medicaid

Medicaid is a health insurance program for the poor. Eligibility automatically extends to persons entitled to benefits under the Aid to Families with Dependent Children (AFDC) program. Most states also extend eligibility to all aged, blind, and disabled individuals who get Supplemental Security Income (SSI) cash assistance. Because Medicaid is jointly funded by the Federal government and the individual states (which have the responsibility for administering the program), there is state-by-state varia-

tion of services offered and of persons considered eligible beyond these "categorically needy" individuals.

In addition to the categorically needy, individuals whose medical bills effectively render them poor ("medically needy") are eligible for benefits in 30 states and the District of Columbia.

In those states linking categorical eligibility to SSI payments (states have the option of using other criteria specified in Title XIX), chronically ill children would be potentially eligible under the disabled category. To qualify for SSI, the individual must be disabled and must not have access to income and resources beyond certain established levels. By law, the income and resources of parents or spouses are deemed available to that individual if they are living in the same household. However, if the individual has been institutionalized for at least one month, he or she is no longer considered to be living in the household. Thus, the relatives' - in this case, the parents' - income and resources do not figure into the eligibility determination.

The concept that a family's resources are unavailable to an individual after one month of institutionalization has undoubtedly allowed many chronically ill children, who would not otherwise qualify for Medicaid benefits, to receive hospital services without requiring their parents to spend down to the poverty line. Ironically, the concept also dictates continued institutionalization for many children who otherwise could and should have been at home for the reason that once at home, they are viewed as having access to family resources which, though sufficient to keep that family above poverty, are woefully insufficient to cover the costs of care.

Pediatric home care is not a benefit which the states are required to provide, though they must offer it if they cover pediatric nursing home care. In turn, if the states do provide pediatric home care (and, according to the 1983 Medicaid data book put together by the Department of Health and Human Services [HHS], all but one state does), they must make certain minimum services available under the program. These services include home nursing visits, medical equipment, supplies, and, as a result of Pub.L. 99-453 (1986), case management and home respiratory care.

There is enormous variation in the degree of home services coverage from state to state because each is given the option of providing (or not providing) additional services. For example, home shift nursing is an optional service. As of 1983, 30 states elected not to provide it. Additionally, there is variation in degree of coverage among required services. All states covering home services under Medicaid must offer intermittent nursing, but the number of covered visits varied in 1983 from 50 to 300 visits per year.

A study of health care expenditures for children with chronic illnesses published in 1985 reported that Medicaid covered only about 60 percent of disabled children below the poverty line. It also concluded that "for parents of modest income with a chronically ill child, it clearly pays to live in some states and not others." According to the report,

> State variations in Medicaid coverage for disabled children are large, ranging from coverage for 10.4 percent of disabled children in families of all incomes in Nevada to 51.2 percent in the District of Columbia. For the low-income disabled, the range is even greater, from 20.5 percent again in Nevada to 86.2 percent in New York. These variations in eligibility and coverage

> represent the situation prior to the 1981 Medicaid amendments. Changes in Medicaid and state fiscal strain have led to reduced eligibility in many states. [Butler, et. al., "Health Care Expenditures for Children with Chronic Illnesses," in Hobbs and Perrin (eds.), Issues in the Care of Children with Chronic Illness (San Francisco, 1985), p.840]

In addition to noting the wide variance in coverage from state to state, the authors of the study concluded that there were serious gaps in private and public insurance coverage and service access for many families, especially those who are near-poor or poor, but not Medicaid or SSI-eligible.

States have four ways under the curent Medicaid system to expand eligibility and covered services for chronically ill children who are able to receive care at home. These four ways are: (1) individual ("Katie Beckett") waivers; (2) Section 2176 home and community-based waivers; (3) Section 2176 model home and community-based waivers; and (4) amendments to the state's Medicaid plan.

Katie Beckett Waivers: Individual, or "Katie Beckett" waivers were developed in 1982. The Department of Health and Human Services accepted applications for such waivers for a period of two and one-half years, from June, 1982 through December, 1984, although some applications were still being acted upon in 1986. Once it received an application from a state Medicaid agency, an HHS interdepartmental review board decided whether or not to apply the usual SSI deeming rules to the individual case in question. In order to waive those rules, the board has to conclude that if the individual received home care, there would be a consequent reduction in Medicaid expenditures and that the quality of care would be at least as good as what was available in an institution.

If a waiver was granted, it remained in effect until the individual either no longer met SSI's disability definition, the family's income dropped below the SSI or state supplemental standard, or the individual turned 19 and qualified for Medicaid and SSI as an adult.

As set forth in the Federal Register, 47 FR 24274, the "Katie Beckett" waiver was meant to fill the gaps while states either amended their Medicaid plans or applied for 2176 waivers. It provided individuals who qualified for only the regular Medicaid services of that state. Thus, if a state did not have home care benefits, the individual waiver option was difficult to use absent other available sources of home care benefit financing.

Section 2176 Waivers: Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (Pub.L. 97-35) authorizes states to finance home or community-based non-institutional services, other than room and board, in lieu of nursing home care for specific target populations. Only Medicaid recipients who would otherwise require institutionalization in a skilled nursing facility (SNF) or intermediate care facility (ICF) or who would require continued hospitalization, SNF or ICF care because of ventilator dependency are eligible for services under the waiver. (See Pub.L. 99-272 [1986]). Among those services which a state may request are case management, homemaker-home health aide services, personal care, adult day health, nursing, medical supplies and equipment, habilitation services, respite care, and others.

The state applying for a 2176 waiver must meet certain requirements. One of these is a showing that, under the waiver, the average per capita expenditure estimated by the state in any fiscal year does not exceed the average per capita expenditure that the state reasonably estimates would have been made in that same year

213

without the waiver. The state uses a prescribed formula, set forth at 20 CFR 441.303, to make this showing.

The state retains flexibility under the 2176 waiver program for determining eligibility for participation. For example, it need not operate its plan on a statewide basis. It may also establish limits on the amount, duration, and scope of services provided to recipients of the waiver as compared to services made available to Medicaid recipients generally. The state may, in addition, set a per capita ceiling on the total cost of each recipient's care and may establish a cost-sharing requirement for individuals eligible for Medicaid solely by virtue of their institutionalization. Once the state has determined its eligibility criteria for the 2176 program, all individuals who apply for it and meet those criteria must be accepted until a projected limit is attained.

HHS grants 2176 waivers for home and community-based services for an initial term of three years. Prior to enactment of the Consolidated Omnibus Budget Reconciliation Act of 1985, waivers were renewable for an additional three years unless the state had not complied with the established program requirements. Under the COBRA Amendments, waivers expiring during the year beginning September 30, 1985, could be extended for one to five years. In addition, starting September 30, 1986, waivers could be extended for an additional five-year period.

Model 2176 Waivers: Because of the long and detailed application process for 2176 waivers, the Health Care Financing Administration (HCFA) developed a "model" waiver. Its purpose, according to the State Medicaid Manual, was to assist states in using the 2176 waiver program to avoid unnecessary institutionalization and reduce expenses.

States may use the model waiver for disabled children (and adults) who would otherwise be ineligible for Medicaid while living at home because of the SSI deeming rules. Under the model waiver, a state must offer at least one home and community-based service in addition to those services already included in the state's Medicaid plan.

All statutory and regulatory requirements applicable to the regular 2176 program also apply to the model waiver. In addition, states are limited to a total of up to 50 cases per model request. To cover larger numbers of recipients, a state must either use the regular program or submit an additional model request. Also, unlike the regular 2176 program (which relies on per capita calculations), a state using the model may admit only those eligible individuals whose estimated home care costs are below the estimated costs of institutionalization.

Model waivers allow a state to work with a targeted group of the disabled population on a small scale. This scale makes it possible for the state to demonstrate case-by-case savings, but it also means that a state must apply for more than one model waiver in order to adequately serve a disabled population of any size. As of July 31, 1986, nineteen model waivers in fourteen states had been granted to serve children. However, even in these states which have model waivers, many children who could benefit from home care are unable to obtain it. For example, the state of Georgia has a model waiver to assist ventilator-dependent children, but only three of the many who meet the eligibility criteria have been accepted into the program. Scores of others remain in hospitals, unable to get sufficient funds to go home.

The waiver system presents the additional problem of compounding an already stressful situation with bureaucratic red tape that discourages all but the most persistent of parents. For example, Jenny Kruse, a near-drowning victim, was brought

home from the hospital by her parents. Her home care costs were 33% below her hospitalization costs, but were still higher than the Kruses could afford out-of-pocket. The Kruses were told by both the Minnesota and federal HHS offices that they would qualify for a "Katie Beckett" waiver and/or 2176, a waiver for chronically ill children. HHS informed Senators Laxalt and Boschwitz that Jenny had been approved for funding, but when the Kruses called to confirm, they were told that their applications were still pending, although they had been on file for months.

Jenny's mother, Dana, told a Senate committee later that:

> The reams of rules and regulations is so mind boggling and discouraging that unless you become determined to sort your way through the maze, you give up...If we choose to institutionalize Jenny, the state would pay for her care and all related medical costs and equipment. Because we choose to keep her home, we have to constantly battle for financial help that is at the very least degrading and often humiliating.

Amendments to State Medicaid Plan: Under Pub.L. 97-248, a state may amend its Medicaid plan to provide regular Medicaid coverage to disabled children aged eighteen or under who live at home and who, because of SSI deeming rules, would otherwise be eligible for Medicaid only if institutionalized. As with the model waiver program, a state must determine that the cost of home care for each child is less than it would be in an institution. The state must also determine that home care is appropriate for each child. All children meeting the state's eligibility criteria must be allowed to participate, but the state may discontinue the program at any time. Although this approach saves the state the cumbersome process of applying for a waiver, it allows for provision only for regular Medicaid coverage. Thus, if a state has little in the way of home care benefits, the amendment will do little to assist pediatric patients.

2. Title V

Another source of federal funding is Title V of the Social Security Act, the Maternal and Child Health Services Block Grant, 42 USC Sec. 701 et. seq.. Amendment by the Omnibus Reconciliation Act of 1981, P.L. 97-35, Title V authorizes the appropriation of funds for consolidated health programs, including services for maternal and child health and for crippled children. Title V also allocates funds for the purpose of enabling the Secretary of HHS to provide for Special Projects of Regional and National Significance (SPRANS). Broadly speaking, these SPRANS grants focus either on training personnel for health care and related services for mothers and children or on research relating to maternal and child health services or crippled children's services.

The Title V block grant gives each state considerable leeway with respect to how its allotment of monies will be spent. A 1984 study by the General Accounting Office (GAO) suggests that the states have used this flexibility in program spending to increase expenditures for crippled children's services and/or to expand upon the services offered.

Originally, the Crippled Children's Services program was directed to children with orthopedic handicaps. However, state programs have extended their concerns to physically disabled, sensory impaired, developmentally delayed and chronically ill children and their families, according to Dr. Vince Hutchins, the Director of Maternal and Child Health of the Health Resources and Services Administration, HHS. The GAO reported that crippled children's services are oftimes provided on a fee-for-services basis

through state health agencies and physicians. Screening, diagnosis, surgical and other corrective procedures, hospitalization and aftercare, as well as speech, hearing, vision, and psychological care, are among the services offered, said the study. In addition, some states have directed funds to case management programs.

Crippled children's services programs appear to be largely clinic-based, but some limited home care services are also available. SPRANS funds were also used in three states, Illinois, Louisiana, and Maryland to develop systems of regionalized care focusing on ventilator-dependent children.

These grants focused on the transfer of children from institutional settings to home settings through the use of multidisciplinary teams. All three projects emphasized the need to develop and sustain a community-based support network. In Maryland, the project combined local, state, and regional organizations to create a private, not-for-profit entity to facilitate the discharge of ventilator-dependent children to their parents or guardians for care at home. Louisiana's program is based at the Children's Hospital of New Orleans. It creates an advisory council consisting of third party payers, state and community agencies, and parents, and focuses extensively on training of the caregiver who will have primary responsibility for the child transferred from an institutional setting.

In Illinois, a non-profit organization coordinates the establishment of a regional system for facilitating the transfer of hospitalized ventilator-dependent children to a non-institutional setting. The Illinois project promotes development of medical, nursing service, case management, financial, equipment, family home care, community involvement, and hospital discharge plans. A SPRANS grant also went to the University of Chicago to study the financial and psychosocial impact on families of caring for their ventilator-dependent children at home and to determine whether the three state programs could be used as models in other communities with other types of chronically ill or disabled children.

3. Title XX

Title XX of the Social Security Act, 42 USC Sec. 1397, et seq., authorizes block grants to the states for various social services. The states are encouraged to target programs which, among other things: prevent or remedy neglect or abuse of children unable to protect their own interests; preserve or reunite families; prevent or reduce inappropriate institutional care by providing for community-based and/or home-based care; secure referral or admission for institutional care when other forms of care are inappropriate. Homemaker-home health aide and transportation services are among those which may be provided under Title XX to supplement medical services furnished through Medicaid.

4. CHAMPUS

The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) pays for care for dependents of active and retired military personnel when that care cannot be obtained in a military hospital. However, CHAMPUS does not pay for "custodial care." That term is defined to include care given to anyone who is physically disabled when the disability is expected to continue and be prolonged. It also includes care to someone requiring assistance in activities of daily living, care to someone requiring a monitored or controlled environment, and care to someone who is not under active and specific medical, surgical, or psychiatric treatment which will reduce his/her disability to the point where the individual can function outside of the monitored or controlled environment.

Many chronically ill children or pediatric accident victims fall within the definition of "custodial care" because their disabilities are of continuing duration. In these cases, CHAMPUS pays only minimal home care benefits. Additionally, the Department of Defense, which administers CHAMPUS, will not pay for custodial care even when it is rendered in a hospital. In other words, if a military hospital determines that it will no longer provide care to a chronically ill or disabled child, that child and his/her family must seek care in the community because CHAMPUS will not pay for it either.

CHAMPUS will pay for some equipment and supplies used in the home, including nutrition and respiratory equipment. Handicappped dependents may be entitled to benefits under CHAMPUS's Program for the Handicapped, but only after they have demonstrated an inability to obtain services from other public programs. Benefits under the Program are capped at $1,000 per month. Home care, supplies and equipment, and physical, occupational, and speech therapy services are covered, but shift skilled nursing is not.

5. Private Sources

Various public and private charities exist which address the needs of some portions of the pediatric population. The Juvenile Diabetes Foundation and the Muscular Dystrophy Association of America are two of the better known organizations that help to fill the funding void. Obviously, however, the impact of these organizations is limited. Children with disorders which do not fit within the charities' criteria will still have to look to other sources of assistance.

The primary source of funding for pediatric home care in the private sector is insurance. According to the Current Population Survey, U.S. Census, March, 1984, just over sixty-four percent of children aged zero to twelve had some form of private health insurance. Such insurance may be the result either of the family's direct purchase, or, more likely, it may be furnished through an employer-sponsored group health plan.

The presence or absence of private insurance appears to be geared largely to income status of the family. The survey showed that race has less to do with the probability of coverage than does the marital status of the mother, with children of single mothers being more likely to be uncovered by private insurance than their counterparts with two parents.

Of course, the absence of private health insurance does not automatically mean there is no coverage for children; they may receive benefits under Medicaid or one of the other government programs discussed above. However, it is likely that anywhere from seven to ten million children have no health insurance of any kind.

It may also be stated with relative certainty that chronically ill children are less likely, on average, to have private health insurance than children without any limitations in their daily activities. There are several logical reasons for this assumption. First, many employer-sponsored group plans (the prime source of private insurance) exclude pre-existing conditions. Second, many policies have lifetime caps which are easily and rapidly exceeded by the chronically ill or severely disabled child. Finally, the policies may simply not cover the particular conditions involved.

Adequacy of insurance coverage is another issue, assuming that the child is covered by private insurance. Several factors in the policy itself are important in assessing the extent of the family's potential exposure: (1) the deductible amount; (2) the co-insurance rate (i.e., how much of the covered services must the family pay

for?); (3) catastrophic stop-loss on out-of-pocket expenses (i.e., a cap on the family's out-of-pocket payments); (4) coverage limits (either annual, per episode or lifetime); and (5) limits on covered services.

Several studies, including one published in 1985 by the Bureau of Labor Statistics (BLS) of the Department of Labor, suggest that the large majority of plans have overall plan maximums. The BLS study, for example, found eighty-two percent of covered employees in 1984 were subject to such maximum amounts. Between fifty-two percent and fifty-seven percent of covered employees had lifetime maximums of $500,000 or less, an amount quickly dissipated by the medical expenses of a chronically ill child with acute episodes.

The BLS study revealed that, of the covered employees sampled, seventy-six percent had a stop-loss catastrophic limit. However, where the beneficiary is a chronically ill child or one severely impaired by accident, the existence of that limit only protects against financial chaos in the short-term. Because the insurance policy most likely has a lifetime benefit limit, the family caring for such a child over a period of years may inevitably face financial crisis except in those rare cases where its assets are virtually unlimited.

About fifty percent of employees covered in the BLS study had no home care benefits. Even where such benefits were provided, most plans had limits on the number of visits covered. A report by Blue Cross/Blue Shield revealed a median limit of ninety visits per year with only seven plans covering at least two visits per week.

Where plans do cover home health care, there are also some gaps in services provided. The Blue Cross/Blue Shield study reported that all such plans covered physical therapy, but only seventy-eight percent covered respiratory therapy: a significant hole in coverage to someone with cystic fibrosis, for example. None of the Blue Cross/Blue Shield plans in the report covered hourly ("shift") nursing as a regular home health care benefit.

Even when a family has private insurance, there is no guarantee that the benefits might someday change, leaving the family in a nightmare situation they could never have imagined. That is precisely what happened to the Fischers of Grand Rapids, Michigan.

The youngest of the family's six children, Katherine, was born with a genetic defect called Trisomy 18. She does not hear or speak or turn over in her bed. She suffers from heart, kidney, and intestinal ailments, and is prone to seizures. Her condition requires long-term catastrophic care, and her recurring deteriorating heart failure demands constant skilled nursing assessment.

Beginning in 1976, the Fischers were insured under the Postmasters Benefit Plan, available through Mr. Fischer's employment with the U.S. Postal Service and underwritten by Prudential. This plan was the most comprehensive one available to the Fischers. It covered up to 364 days per year for care in an acute care facility or an extended care facility. Prior to 1983, the plan also covered the majority of expenses incurred for home care. Specifically, the plan paid for eighty percent of the cost incurred up to the first $10,000 and one-hundred percent of amounts in excess of $10,000.

In 1983, the plan changed its benefits for private duty nursing in the home by placing a $10,000 yearly cap on benefits. The benefits for institutional care did not

change. Along with other insured families, the Fischers got a one-year waiver on imposition of the $10,000 limit, but it went into effect in 1984.

Until the time of the change, the Fischers had handled Katherine's care themselves because they wanted and were able to do so. But then, just as they reached a point where they needed to invoke the benefits of their insurance plan, those benefits were altered. Katherine's medical condition worsened that year, and she was hospitalized twice in the fall. Her second hospitalization lasted six weeks, and she was discharged on Chirstmas Eve as a hospice patient.

At that time, Katerine's doctor didn't expect her to live more than a few months. The Fischers wanted to keep her at home, but her weakened condition demanded more care than they could provide alone. After all those years when they didn't use the benefits available to them, now, when they really needed them, they had to contend with a $10,000 cap. The money was gone by early May, and it lasted that long only because the Fischers provided virtually all of the care themselves. They received 150 hours of crisis intervention nursing through Michigan's Crippled Children's Program, but that expired the first week of June. They applied for a model home and community-based waiver, but were rejected by the state's Department of Social Services because Katherine was Medicaid-eligible and because the cost of her home care would not be less expensive to the state than institutional care (since that was covered by private insurance).

In July, 1984, the Fischers temporarily had to rehospitalize their daughter because the strain placed on them by providing 24-hour care was compromising her medical condition. They didn't want to put her back in an institution, but they had no choice. In the meantime, they requested support from every agency and every official they could think of. They were eventually able to get $10,000 from a state mental health waiver by virtue of Katherine's mental disability. That was only a partial solution. Until Prudential finally agreed in 1986 to waive the limit on home care, the Fischers were faced with the constant emotionally and physically exhausting tasks of caring for their daughter, conserving dwindling resources, and reassessing whether to maintain her at home, with the possibility of compromising her care, or reinstitutionalizing her. As Mrs. Fischer pointed out in testimony before Congressman Claude Pepper's Health Subcommittee of the House Select Committee on Aging, their family had done everything they could to prepare for the future, but a change in insurance coverage wiped out their efforts.

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Legislation introduced by Senators Kennedy and Hatch in the 99th Congress addressed some of these insurance concerns. Their bill, the "Alternatives to Hospitalization for Medical Technology Dependent Children Act of 1985," S. 1793, was aimed at employee health benefit plans that do not cover medical or other services necessary to care at home for a child whose life is dependent on medical technology. By virtue of the Employee Retirement Income Security Act (ERISA), such plans are immune from state legislation. (Only about a dozen states require health insurance companies writing self-purchase plans to offer home health benefits.)

S. 1793 would have convened an Office of Technology Assessment (OTA) task force charged with developing a model plan for coverage of pediatric home care. The model would specify services to be covered for the eligible population, which consisted of children up to age 21 with a medical condition requiring hospitalization for one month, but for the provision of home care, and who are eligible for inpatient hospital coverage under an employee health benefit plan. The legislation also declared that insurers would not be required to make expenditures for home care greater than those for

hospital-based care and that they could place no limit on total payments for home care which was less than any limit placed on payments for inpatient hospital services.

S. 1793 mandated coverage of the type set forth in the model if, one year after the OTA's recommendation, less than eighty percent of employee health benefit plans offered similar benefits. Other provisions of the bill dealt with monitoring and with authorization of $20 million to Title V agencies and other groups to develop community-based services, training, and technical assistance programs.

The bill introduced by Senators Kennedy and Hatch was obviously limited in scope; it affected only tecnhology dependent children with hospitalization coverage through an employee health plan. Still, it was a significant start in the right direction, and will hopefully be revived in the 100th Congress.

Several states have developed pooling arrangements to insure high-risk individuals, including children, up to a maximum cost amount. Most states (forty-four as of 1985) have enacted legislation to require all group coverage policies to provide for care of newborns. Prior to such legislation, many insurance policies suspended coverage for the first two weeks of life while the insurer determined whether to pay for potentially catastrophic neonatal care. As of 1985, thirty states had also passed laws which prohibit exclusion of chronically ill or handicapped children from benefits when such children are born to parents covered by a family plan.

Some insurance companies have also explored alternatives to the current coverage situation. One example is the Individual Case Management (ICM) Program of the Aetna Insurance Company, Hartford, Connecticut.

Dr. Thomas Culley, Medical Director of Aetna's Employee Benefits Division, and Barbara Matus, RN, its Cost Containment Coordinator, reported to Foundation staff that rising health care costs were the impetus for creation of the ICM program. According to Matus, "[W]e were spending an awful lot of money, but not necessarily in the right environment...We were, for years, hearing from physicians who would identify less costly alternatives, but we were so bound by the insurance contract that we were not able to do anything about those cases." As a result, she said, Aetna developed the Individual Case Management Program in 1983 to identify alternatives to very costly methods of treatment or places of treatment.

Dr. Culley explained that:

> [T]he trend that runs through most of these cases is that there are a significant number of people who are in need of hospitalization because they are in need of a certain level of nursing care or because they are in need of certain equipment that is traditionally available only in certain kinds of facilities. But their progress is such that they are not in need of daily changes of medications, care, to the extent that they need to have a lot of physician input.
>
> When the patient reaches that point, where they are more or less stabilized, they may be stabilized at a level requiring a great deal of care, and even to the extent of being in the intensive care unit. But that care could be replicated in the home in some instances, in a less costly manner than in the hospital. There has to be the fact, though, that the care can be replicated in the home. And it has to be acceptable to the physi-

cian, to the patient, to the employer, and has to in no way decrease the quality of the care.

It is cases of this nature that the ICM program seeks out. Aetna reviews the insurance plan to see if coverage is provided for such alternatives as home care. Even if there is no coverage of that type, the ICM program will pick up the appropriate care costs by going outside the insurance contract itself. "What we are basically doing," Culley pointed out, "is allowing the physician and health care personnel to tell us what sort of level of care the patient needs, and then we can modify ourselves to meet the patient's needs, rather than having to modify the care to fit our predetermined plan."

Matus indicated that the ICM program handled approximately 600 cases in 1985. She estimated that half of those involved children from birth to eighteen years of age. The nature of cases handled showed considerable variation: high risk infants, infants born with respiratory difficulties and other congenital anomalies, and teenage quadraplegics who were the victims of accidents.

In one instance, a six-month old infant girl with Zellweger's Syndrome and seizure disorder had been hospitalized since birth. With approval of the policyholder, Aetna's ICM program arranged for home care and for payment of non-covered expenses for training of home nursing personnel, supplies, increased electricity expenses resulting from ventilator use, and home health aide visits over and above the policy's 120 visits-per-year maximum. ICM reported that $20,000 per month was saved on this case by avoiding inpatient hospital expenses.

Another case involved a twelve-year old girl who spent two years in the hospital for treatment of cerebral aneurism and a brain tumor. Aetna covered her round-the-clock nursing care at home at another savings of $20,000 per month. Altogether, Culley and Matus estimated that the ICM program resulted in a $36 million reduction in costs in 1985.

The benefits of a flexible private insurance program like ICM are measured in terms other than dollars. As Dr. Culley pointed out, the pediatric population is particularly amenable to an approach of this type "simply because the environment of the home is so important to the child and because...the child's changing needs and the need for the changing environment...can be hindered by continued hospitalization."

The obvious question is why other insurance carriers do not adopt an approach like Aetna's if, in fact, the cost savings are so dramatic. The answer is that others, including Equitable and John Hancock, have developed similar programs designed to evaluate alternative care plans. In the case of the Fischers, Prudential also demonstrated a willingness to accept this approach. But the insurance industry, like any bureaucracy, is slow to change, and a plan such as ICM requires an abandonment of traditional notions of the sanctity of the insurance contract. However, the evidence is that such re-evaluation of the standard insurance policy is forthcoming.

III. ARGUMENTS IN FAVOR OF HOME CARE, INCLUDING COST EFFECTIVENESS

The principal inquiry in any analysis of pediatric home care should be whether its effectiveness is equivalent or superior to care in alternative settings. Ultimately, our national obligation is to pursue a healthcare policy that places the interests of the patient and his or her family above all others.

Certainly home care offers a number of advantages over institutional care. It can reduce the risk of infection by removing the child from an environment in which he or she is necessarily exposed to other diseases. In that respect, home care can actually be safer than care in the hospital. Home care also provides the child with a positive environment which, in turn, promotes the healing process.

Home care obviously helps keep a family together. In so doing, it may help to remove some of the stress otherwise borne by parents who must divide their attention between an institutionalized child and his or her siblings.

Home care has the potential for offering the chronically ill or severely disabled child an enhanced quality of life. It also appears to be a cost-effective alternative in the vast majority of cases.

Still, home care is not always going to be the appropriate solution. Some patients will require continuous monitoring, making a hospital the most logical locus of care. Others may be in a position to go home, but for a variety of reasons their families are unable to provide proper care and support. In some instances, patients who are already at home may need rehospitalization during acute flare-ups or for treatment of a compounding condition. And there may be times when a brief return to a hospital, skilled nursing facility, or intermediate care facility is the only way to provide family caregivers a respite from their responsibilities.

Any rational policy with respect to caring for these children must be formulated in such a way as to permit institutionalization or reinstitutionalization when necessary to maintain their health. Transferring of these patients to the home setting should not be a one-way street. This means that a comprehensive system of funding must be designed so that the return to an institutional setting, whether for a day or a month, will not adversely impact on the patient's eligibility for assistance either then, or when the patient is subsequently ready to return home.

Despite these caveats, care in the least restrictive environment -- the home -- should be the goal whenever appropriate. It is the best solution for keeping a family together, for providing a stimulating environment for the pediatric patient, and for creating the supporting and loving atmosphere that should be every child's birthright.

Albert Einstein College of Medicine-Bronx Municipal Hospital Study

In addition, home care may often be the best solution from a medical and psychological standpoint. Scientific evidence in favor of one care alternative or the other is hard to come by; however, the best study to date, reported in the June, 1984 issue of ***Pediatrics***, concluded that pediatric home care made a positive difference for children with a chronic illness.

The study was performed in conjunction with the Albert Einstein College of Medicine-Bronx Municipal Hospital, Bronx, New York, and evaluated the hospital's Pediatric Home Care (PHC) Unit. According to its authors, Dr. Ruth E. K. Stein and Dr. Dorothy Jones Jessop, the study resulted from the fact that "[a]lthough there has been significant biomedical research geared to prevention, treatment, and cure of specific conditions, there has been little research aimed at ameliorating the secondary psychological and social consequences of chronic childhood illnesses and understanding the psychological and social effects of alternate forms of health care delivery." ["Does Pediatric Home Care Make A Difference For Children With Chronic Illnesses?", *Pediatrics* 73-845-53 (June, 1984)]

The PHC program provides comprehensive and integrated medical, psychological, and social services for a wide range of children with chronic illness. It was organized on the premise that the concerns of families with chronically ill children crossed specific disease categories, and it seeks to involve the family in taking responsibility for increasing aspects of management and informed decision-making with the health care professionals. The PHC's services include monitoring of the patient, delivery of direct services, teaching of therapeutic programs to both family and patient, coordination services, patient advocacy, health education, and support. Care is administered by an interdisciplinary team consisting of a pediatrician, pediatric nurse practitioner, and the patient's family.

The researchers developed a pretest-posttest experimental design for evaluation under a grant from the Maternal and Child Health Crippled Children Services Division of HHS. Children with diagnostically heterogeneous chronic physical conditions were assigned in random fashion either to the PHC program or to the standard care available through the hospital. The researchers then obtained data, through a series of structured interviews held at specified intevals, which focused on: (1) satisfaction with care; (2) child's psychological adjustment; (3) mother's psychiatric symptoms; (4) impact of the illness on the family; and (5) child's functional status.

Drs. Stein and Jessop concluded that:

> pediatric home care is effective in improving the satisfaction of the family with care, in improving the child's psychological adjustment, and in lessening the psychiatric symptoms of the mother. The functional status of the children was equally well maintained in both groups, and there was no significant difference in the impact of the illness on the family between the two groups...Such a home care program can be an effective intervention for minimizing the social and psychological consequences of chronic illness. [Id.]

Clinicians' Comments

There have been a number of articles in various medical publications, including the *Journal of Pediatrics*, in which clinicians have contended that home care is more advantageous than institutional care for medically stable children. These articles have expressed the beliefs of their authors that children who are cared for at home make faster medical and developmental progress than their counterparts in hospitals. [See, e.g., Goldberg, et al., "Home Care for Life-Supported Persons: An Approach to Program Development," Journal of Pediatrics 104:785-95 (May, 1984)]

These opinions in the literature were reflected time after time in interviews of pediatricians and other caregivers conducted by Foundation staff. Obviously, the frame

of reference is partly subjective. It is significant, though, that there was a consistency of opinion among experienced members of the medical profession who had studied and treated numerous cases in both the home and institutional settings. Equally important is the fact that many of these doctors had also witnessed dramatic changes in progress by the same child when he or she was moved from the hospital to the home.

Among the comments made to Foundation staff during the course of this study were the following:

- [W]e duplicated this observation in every child that we have sent home, and that is that you accelerate his development massively, not only their [sic.] development in terms of intellect and muscle and motor tone, but also their medical status. And in most of these cases, the kids have some form of respiratory problem. The kids that we have sent home, their respiratory stratus has improved markedly at home.

- Children do better at home. Their families do better, they learn more, they seem to make more gains just by being in a home environment. No matter how much you try to set up the hospital room, it is never like being at home.

- [W]e had one child, for instance, who very honestly had a very, very rocky newborn course. He was on a respirator for a long time and finally came off and went home but came back in and then was in the hospital for months and months and months. And developmentally, he was not doing well at all.

  This kid walks around the house, plays with his brother, and I mean the developmental difference -- and I -- you know, someone says, "How do you know that was in the home, that might have happened in the hospital?"

  I don't believe it. I think that the major ingredient in that child's getting better was not just the coincidence of time. I think it was the difference in the developmental and psychological environment that can only be produced by the home.

- [W]hen you take the child and you bring him home,...all of a sudden the responsiveness to those initiatives start to take off. So we don't have the requisites for the developing child in the hospital.

- We have repeatedly demonstrated with our kids that that sort of nurturing is much better in the home than it is in the hospital setting.

- [J]ust a general philosophical observation, and that is that it seems a shame to waste the potential of children by keeping them locked and bound to institutions when, in fact, we can put them in a home care setting with their families where both the family and child want to be, and enhance their recovery.

- We have several children who have different diseases, but basically the same problem, that being ventilator dependent [children] who are in the home setting. All of these children have made tremendous developmental gains since they have been home. They have picked up normal skills that children learn, such as walking and so forth, which we were unable to achieve here in the hospital and they have achieved in the home setting. And the reason for that is because of the normalcy of the home nurturing environment which we cannot duplicate here in the hospital setting as much as we try.

  Now, in the case of Ryan, when he left the hospital here, after being here for three years, [he] was not walking without help, and he was not, did not have the motor skills that he has now. His speech has markedly improved, and all of these things have been learned at home in the normal home environment.

* * * *

Clinton is another young man who has multiple major congenital problems and the one problem that has made him hospital bound in the past is, like Ryan, his respiratory status. And Clinton also has been home on the home program, not as long as Ryan, but has done very well. And he, intellectually in particular, and to some extent in terms of motor skills, has made advances far beyond what we thought he would.

- Our experience is that in terms of infection, in terms of nutrition, and in terms of the child's development, including cognitive development, the home is a better place than the hospital.

- [T]here is nothing you can do to this institution to make it into a home. Now, we have tried to make a step by doing some special things. We have a special area within our nursery where our long-term kids are kept. This is an area that has evolved, really by an interest in our developmental specialists and in the nurses, for trying to give these children an infancy and childhood with their health care in the background. But that still is not home, and we have found, virtually every time, when we have taken a child and successfully were able to do the logistics of getting home care arranged, that that child makes incredible adaptations into the home situation, both physiologically and, more important, developmentally.

Cost Comparisons

The case for pediatric home care is best made in human terms, in the advantage to the handicapped child and to his parents and siblings of a warm, personal, and loving environment. As discussed elsewhere in this report, medical experts feel that the child's prognosis is improved when he or she can be cared for in the home. Not

only does the physical and emotional support that the family unit can provide help to relieve some of the stresses and strain which necessarily result from a serious chronic illness, but it also appears to be the case that the child's medical condition actually improves in many instances. The growth and development of Katie Beckett, for example, have exceeded the most optimistic expectations. The chance she has had to interact with her parents and with other children has contributed in no small measure to her miraculous advances.

However, the advantage of home care over hospital care can be measured in monetary terms as well. Study after study reveals that proper care can be afforded the chronically ill child at home for a fraction of the cost of institutional care. Katie Beckett's transfer back to her home saved the government approximately $10,000 a month over the cost of treating her in the hospital. A few of the other documented case savings are set forth below:

A. Sonia S.

Sonia was ten years old when she was struck by a car while crossing a street near her home in Indianapolis, Indiana. An off-duty fireman kept her alive by providing artificial ventilation at the scene of the accident. Once she reached the hospital, Sonia was saved by the recent advances in emergency medicine, critical care, and respiratory rehabilitation. She suffered a complete severance of her spinal cord at the level of C2, an injury that until just a short time ago, resulted in death. Sonia's injury left her a quadriplegic who needs permanent total lifetime reliance upon a ventilator.

Institutional care for ventilator-dependent cord injured persons is costly. An alternative for care, particularly for children, is home care. In Sonia's case, the cost effectiveness of that option was dramatic.

During her eight months of hospital care, Sonia's costs amounted to $291,411. Once she was medically stabilized in the hospital, the monthly costs ranged from $22,000 to $34,000 - an average of $29,113 per month. At home, the costs for Sonia's care during the first month was $19,921, reflecting expenses relating to the purchase of equipment and 24-hour private duty nursing care. For subsequent months, expenses averaged $5,281. This amount consisted of the rental of equipment, the purchase of supplies, fourteen-hour-per-day private duty nursing costs, and related transportation expenditures. The bottom line is that for an eight month period comparable to the length of Sonia's hospital stay, home health costs were $56,327, just nineteen percent of the total hospital costs. The average monthly cost after the first month of equipment purchase and services was $5,281, eighteen percent of the average monthly cost in the hospital after stabilization.

B. Marvin G.

Marvin is a teenager living in Oklahoma. When he was fifteen, he was popping wheelies on his bicycle - a common activity among fifteen-year old boys. Marvin, though, fell and sustained a high spinal cord injury. He was left a quadriplegic, with no movement or sensation below his neck. Marvin is also unable to breathe on his own.

He was in the hospital for eight months, during which time his medical bills totalled $194,000. The State of Oklahoma, through its Crippled Children's Services program, pays for Marvin's supplies and equipment at a cost of about $200 per month. First, though, his family of five, with an average monthly income of $1,100 must spend

down $470 per month and must pay for all out-of-pocket medical expenses. His nursing care, if he were to have the amount needed to assist his family to care for him, would cost approximately $800 per month. No program picks up these costs. The absurd result is that a combination of federal and state dollars covered more than $24,000 per month of institutional costs, but will pay only $200 per month to help keep Marvin at home with his family.

C. Robert B.

Robert was born in 1983. He suffers from a rare and severe form of muscular dystrophy and requires the assistance of a ventilator to breathe.

Robert's father, Mike, is in the U.S. Navy, and was stationed in Virginia when Robert was born. Robert spent eight months at Children's Hospital of the King's Daughters in Norfolk. However, when his parents talked to the hospital in October 1983 about the possibility of bringing Robert home, they were told that neither the hospital nor the State of Virginia had the necessary resources to enable them to care for their son properly. Mike and Angie B. were forced to move their family to Washington, D.C. where Robert could enter the home care program at Children's Hospital National Medical Center.

The military's health insurance program, CHAMPUS, paid for Robert's stay in the hospital intensive care unit.

According to his mother, Angie, the cost of this care was $1,200 per day, or $438,000 per year. In addition, physicians' costs in the hospital came to $18,000 per year: a total of $456,000. Robert's home care costs were $67,500 per year, under fifteen percent of the pricetag for hospitalization. Yet CHAMPUS capped home care payments at $1,000. not enough to get Robert out of the hospital.

D. Lauren C.

Lauren has a mal-absorption problem and is dependent on an infusion pump for her nutritional needs. Her family had to move twice before it found a state (Massachusetts) that covered Lauren's care. While in the hospital, Lauren's bills averaged $320,000 per year. Her home care cost is estimated at one-third that amount.

E. Baby Jones

Baby Jones was born prematurely in Salt Lake City, Utah. She needed a ten-day IV antibiotic therapy treatment. The cost to Medicaid for having this treatment provided at home by a home health nurse on a twice-a-day basis would have been about $65 per day. However, Utah's Medicaid program specifically excluded twice-a-day home health nursing care and therefore refused to pay for the treatment at home. Instead, the baby remained in the hospital for the ten days at a cost of between $150 and $300 per day.

F. Sally G.

Sally was an eight-year old who went into a diabetic coma lasting for two months. When she awakened, she was unable to move or speak. After four months of hospitalization, Sally was discharged to her home. At that time, she was totally bed-

bound, with a feeding tube and a tracheostomy. The home care program, which began the day of her discharge, included speech, nursing, occupational and physical therapy.

Fifteen months later, Sally had no feeding tube and was learning to feed herself. She was also learning to speak all over again. Had she remained in the hospital for that period, her care would have cost $286,200. Her home care for the fifteen months cost a total of $22,162. More important, the family relationships and supports that were possible in the home environment could not have been realized in the hospital. Despite these advantages, although her institutional costs would have been completely covered, her home care agency had to subsidize some of the $22,162 until Sally's family became Medicaid eligible.

G. Mary T.

Mary suffered from multiple problems, including lung disorders. Her hospitalization costs at Children's Hospital National Medical Center in Washington, D.C. averaged $62,463. Her home care costs for the first four months averaged $1,500 per month and dropped to $1,000 per month thereafter as her condition improved.

H. Katherine F.

Katherine has multiple impairments, the result of a genetic abnormality called Trisomy 18. Following the deterioration of her condition in 1983, she was hospitalized several times. Her last hospitalization was at a daily cost of $392.55 excluding ancillary services. Her daily rate in the intensive care unit was $725 per day. In contrast, the cost for home care nursing was $200 per day.

* * * *

In addition to these individual care comparisons, there have been a number of institutional studies which also show home care to be cost-effective. The following summaries are examples of these studies.

I. AART Study

A twenty-state hospital survey released by the American Association for Respiratory Therapy (AART) in 1984 found that Medicare/Medicaid are losing millions of dollars annually by not paying for care of ventilator-dependent persons at home. The report of the AART (which represents the nation's 100,000 respiratory therapists and technicians) found the average cost of care for ventilator-dependent persons was $270,830 per person per year in a hospital versus $21,192 per person per year at home.

The AART survey identified 1,992 chronic ventilator dependent patients in twenty states with 258 being identified as being "medically able" to go home. Based on the $250,000 per person annual savings, AART estimated the annual savings for this group alone would be $64.4 million. They also estimated that this group represents only about half of the total ventilator-dependent population which is medically able to go home. The survey defined a "chronic ventilator-dependent patient" as one who requires some ventilator support within a 24-hour period for at least 30 consecutive days.

The survey also gave specific results on ventilator-dependent children age 17 or younger. Of the 1,992 chronic ventilator-dependent patients identified in 20 states,

15.6 percent (or 310) were in the 17 or under age group. Of those, 91.6 percent (or 284) were hospitalized. And of these, 16.8 percent (or 48) were medically able to be discharged from the hospital and appropriately cared for at home.

J. Massachusetts Study

A study of six families with children less than 18 years old was conducted in Massachusetts in late 1980. In each case, the child required ventilator assistance for at least part of the day and lived at home. Each of the parents expressed their belief that bringing the children home from the hospital had a beneficial effect on family relations. The home care costs ranged from $1,000 to $75,000 per year per child, which were fifty to ninety-five percent lower than hospital costs, which ranged from $150,000 to $400,000 per year per child.

K. Children's Memorial Hospital, Chicago

Dr. Allen Goldberg of Children's Memorial Hospital in Chicago presented several case studies of cost-effective home care for ventilator-dependent children at the Surgeon General's "Workshop on Children with Handicaps & Their Families, Case Example, The Ventilator-Dependent Child" held in Philadelphia in December, 1982. The results of those case studies are set forth below:

1. Case I

Patient D.W. - Age at discharge - 3 years, 4 months
Condition: Partially ventilator-dependent
- 1 hour "free time"
- 35% oxygen support
Discharge Date: 9/10/79

Hospital Care Costs
March 1, 1979 - August 31, 1979
184 days (6 months)

Intensive Care	$ 67,550
Pharmacy	990
Radiology	260
Laboratory	1,760
Central Supply	1,490
Respiratory Therapy	65,190
Physical Therapy	2,450
Cardiology	30
Take home drugs	20
Non-covered services	260
TOTAL	$140,000

$140,000 / 6 months = $23,330/month

$140,000 / 184 days = $760/day

Home Care Costs
January 1, 1981 - June 30, 1981
181 Days (6 months)

Nursing	$ 31,680
Central Medical Supply	460
Life Care	1,560
CMH	2,930
RAMED	4,390
Barton Research	870
Marie Lynch	180
TOTAL	$ 42,070

$42,070 / 6 months = $7,010/month

$42,070 / 181 days = $232/day

2. Case II

Patient H.S. - Age at discharge - 1 year
- ventilator at night
- diaphragmatic pacers during day
- no oxygen required

Discharge Date: 6/1/81
Hospital vs. Home Care Costs
6 month Cost Comparison
Private Insurance - Midwest

Hospital Costs 1981	Home Care Costs 1981
$189,250	$45,630
182 days	184 days
$1,040/day	$250/day
$31,540/month	$7,610/month

Dr. Goldberg also noted that in general, the cost of hospital acute or intermediate care has risen by eighty-four percent in the preceding five years, from about $400 per day to about $1,000 per day for acute care and to about $745 per day for intermediate care. The cost for care at home, however, had remained at about $250 per day initially after transfer and in time dropped to under $200.

L. Primary Children's Medical Center, Utah

In the spring of 1984, PCMC did a cost comparison study involving patients in the hospital that could benefit from pediatric home care services. The hospital reviewed patients from all service areas of the hospital, including infant special care, ventilator-dependent children, medical surgical patients, etc. The study concluded that third-party payers combined, including Medicaid, could save as much as $900,000 per year in hospital expenses if these children were involved in home care programs.

M. Illinois Demonstration Program

During an October, 1985 symposium on the ventilator-dependent child, George Koube, Executive Director of Children's Home Health Network in Illinois, discussed the results of a statewide demonstration project in conjunction with the Division of Services for Crippled Children (State of Illinois), Children's Memorial Hospital (Chicago), and La Rabida Children's Hospital (Chicago). The study revealed that over a four-year period, the State of Illinois saved more than $4 million treating ten ventilator-dependent children who returned home. According to Koube, "These savings are based on the assumption that hospital intensive care for a ventilator-dependent child average $30,000 per month, compared with $8,000 per month for home care." Illinois statistics and other data collected by similar home care initiatives nationwide suggest "about a seventy-five percent drop in expenses when a ventilator-dependent child is brought home," Koube said.

N. Maryland Ventilator Project

The Coordinating Center for Home and Community Care, Inc. (CCHCC) reported 1986 average hospital costs of $1,000 per day ($30,000 per month) for children who are dependent on ventilators and other respiratory supports. The estimated cost of home care for these children was $12,000 per month, including 24-hour nursing, all supplies and equipment, and allied therapies.

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The above-referenced studies are not an exhaustive account of the comparisons that have been made between in-hospital care and care in the home. They do, though, represent a consensus of opinion that the home care option is one which can offer significant cost savings.

The dramatic differences in costs are due in large part to over-utilization of services in an institutional setting. For example, a child in a hospital receives 24-hour per day nursing coverage. If that child is in an intensive care unit, the coverage is one-on-one. In a step-down unit, the coverage may be one-to-two or one-to-three. A home health nurse, though, makes a visit two or three times a week maximum for a large percentage of pediatric home care patients. The visit may constitute approximately one hour of hands-on care. The cost difference between three hours per week of hands-on care and 24 hours per day seven days a week is obvious. And of course, this comparison says nothing about the overhead costs of hospital care, such as room and board, which are significantly lower in the home setting.

Less obvious are some of the other reasons why home care is more cost effective than institutional care. The former results in a decreased number of rehospitalizations, in decreased length of hospitalizations, in decreased inappropriate use of the emergency room, in the prevention of complications of the primary diagnosis, and improved medical compliance. These factors, in turn, reduce the overall cost.

VIII. SERVICE COMPONENTS OF PEDIATRIC HOME CARE

Advances in medical technology, coupled with the pending application of DRG's to the pediatric community, have resulted in increasing numbers of medically fragile children leaving hospitals sooner and sicker than ever before. Home care is fast becoming the chosen option for these children. Provision of care in the home to medically fragile children maximizes the child's potential for well-being. The questions that challenge the health care community are: to what degree does pediatric home care differ from the traditional home care approach, and to what degree do our public policies reflect these needs? This country's pride in the provision of optimal care to its children is surpassed only by the unconditional positive value it places on the family unit. Preservation of the family as a vital institution in American society is paramount among our national priorities.

It is for this reason that we cannot afford to view pediatric home care with tunnel vision. The traditional approach to the provision of home care must be expanded when we look at pediatric home care. Failure to recognize and foster the provision of the multiple service components of pediatric home care places the children and families who could benefit from home care at risk. Home care must be viewed in its totality. Physical, technical, economic, social, developmental, and educational needs must all be addressed to ensure that home care is a viable option.

For the medically fragile, technology dependent child, the transition from the hospital to the home can be a complex task. The identification and coordination of community resources available to the child and family are vital in ensuring continuity of quality care. The availability and quality of such resources vary greatly. Many factors, including economics, politics, and societal attitudes, contribute to this discrepancy. Even programs which are financed in part by the federal government, such as Medicaid, have eligibility requirements that vary from state to state. Such lack of continuity and fragmentation of services contribute to the already difficult task of coordinating home care.

Recognition of a family's needs when caring for a medically fragile child is the first step in assuring the provision of necessary services. Regardless of the strengths a family may bring to a crisis situation, a child's hospitalization, home care, and chronic illness constitute a highly stressful situation for both individuals and the family. The extraordinary demands on time, energy, and finances, coupled with the psychosocial issues of caring for a medically fragile child, place the entire family in a position of vulnerability. To maximize the potential for the successful implementation of home care, public policies must reflect the need for long-term availability of the following comprehensive services:

A. Respite Care

Home care demands intervention twenty-four hours a day, seven days a week. Caring for children assisted by oxygen, apnea monitors, ventilators, gastrostomy tubes, tracheostomies and similar equipment is exhausting and draining. These children also require constant medical, emotional, therapeutic, and educational intervention. The toll taken on families who face such a challenge without help can be devastating.

Respite care services, services which provide relief care to children and families, are recognized by recipients of home care and professionals in the field as an integral part of comprehensive pediatric home care. However, throughout the country respite care services are fragmented, limited by population, and non-reimbursable by Medicaid and/or third party insurance. In Maryland, for example, respite care is offered to

families for a maximum of two weeks and/or 140 hours per year. Payment is based on a sliding scale. Eligibility requirements state that a child must be developmentally disabled and require minimal medical intervention. For those children and families requiring more than two weeks per year of assistance, more than minimal medical attention, and/or having limited financial resources, such care is not available.

In Washington, D.C., Lutheran Social Services provides in-home respite care to families and children identified as either at-risk for abuse or who actually have a history of abuse. The program is supported by the National Council on Child Abuse and the Department of Human Services. Medically fragile children are therefore not eligible unless the family is viewed as potentially or actively abusive. Also located in Washington, D.C. is the Kennedy Institute. This in-home respite care program services developmentally disabled children and adolescents. Children requiring medical intervention are not eligible. Once again, the medically fragile child and family are faced with limitations of service availability which increase rather than decrease a family's level of stress and its consequent ability to manage a child's care. The lack of availability of respite care, inconsistent eligibility requirements, and little to no financial assistance contribute to a family's frustration and stress.

B. Alternatives Re: Day Care And Living Arrangements

The trend towards home care for chronically ill children consists of a series of objectives: to help these children move to their homes or to another "best" setting; to maintain the child's medical and social stability in this setting; and to focus on the interests of the child and family rather than on the interests of health professionals, institutions, or third party payers. Home care refers to the effort to place a child in the least restrictive environment - that is, where he or she can best develop while receiving direct care from adequately supported and supportive caretakers. The least restrictive setting may also be cost effective. This sequence of priorities must be retained in the basic definition of home care. Public policy must also recognize that home care is not always feasible. Often there are inadequate financial resources, environmental deficiencies, emotional considerations, or an inability to provide constant and consistent care of such a complex nature.

Additionally, many families experiencing a crisis of one kind or another, such as a parent involved in an auto accident, the birth of a new sibling, or a death in the family, have no alternative but to rehospitalize their child for the duration of the crisis. This is also true for families who desire a family vacation or who need a brief respite from the stress of caring for a medically fragile child. Quality home care must address the needs of home care recipients in the context of a continuum of care ranging from institutionalization to care at home with minimal intervention.

C. Psychosocial Intervention

Common responses to caring for a medically fragile child include:

- parental disappointment, shame, or guilt
- parental resentment or anger
- overconcentration of attention on sick the child resulting in fatigue, depression, and family impoverishment

- distortion of family life with respect to where to live and what to do
- sibling resentment
- sibling grief and depression

These common, normal responses are further exacerbated by financial and case management demands. Without the availability of professional services to deal with these issues, a child and family are prone to separation, unmanageable stress, and rehospitalization. For the inner city family, the problem is worse; already faced with poor housing, unemployment, inaccessible transportation, high-risk neighborhoods, and limited health resources, the presence of a medically fragile child minus the necessary support can tip the scales. Although it is well documented that the intervention of a trained social work professional can minimize the crisis by providing coordination, case management, and counseling, public policies do not ensure the provision of such services.

In October, 1986, the New Jersey State Medicaid Office released a memo to all state agencies administering the Medicaid program. Included was the following statement:

> Medicaid social services may not be covered under Medicaid as a home health service because they are omitted from the regulation's definition of home health services. Therefore, they may not be billed as home health services. Moreover, to the extent that costs of medical social services which are not seperately billed, but are included as administrative costs, are attributable to specific services to specific patients, they also do not qualify for FFP.

Such interpretation is common nationwide. The effects of the restricted use of social work intervention on the families of medically fragile children are devastating. Once again, the question that must be asked is: to what degree do our national policies reflect our national values and priorities?

D. Education

The education of medically fragile children is a relatively new development. As the growing population of technology dependent children approaches school age, we are faced with challenges and dilemmas. Historically, handicapped children have been assured special education privileges under Public Law 94-142. However, as currently interpreted, Pub.L. 94-142 does not meet the specific medical needs of many of these children.

Handicapped children are those children evaluated as "mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, deaf-blind, multi-handicapped, or as having specific learning disabilities, who because of those impairments need special education and related services." "Other health impaired" includes conditions which adversely affect a child's educational performance. If a child's impairments do not interfere with the ability to learn in a regular classroom environment, that child is not

considered to need special education. Because related services are defined as services required to assist a handicapped child to benefit from special education, a child who does not qualify for special education is therefore ineligible for related services. As a result, medically fragile children may not meet the eligibility requirements for P.L. 94-142. These children, however, require extensive services in order to participate in and benefit from school.

One of these services is nursing. For example, consider a ventilator dependent child who receives eight to sixteen hours of daily nursing in the home. This service is covered by insurance. Entrance into a school program requires that nursing assistance continue during school hours. Such coverage is rarely provided by insurance or educational policies. Who then pays for the medical coverage necessary to allow the child's participation in a school program? Or, consider a child receiving eight hours of nursing care at night. The family has selected this shift of nursing care to allow continued daytime employment and nighttime rest. Entrance into a school program requires the addition of eight hours of nursing care, yet the increase is not covered by insurance policies. The family is forced to assume nighttime care without support in order to allow the child to enter a school program.

Therapy is another service the provision of which is complicated by the needs of the medically fragile child. Therapy is provided by school personnel to the extent that it complies with a child's Individual Education Program (I.E.P.). However, chronically ill, technology dependent children have long-term medical and rehabilitation needs requiring daily intervention. These services are rarely available through the school system. Continuation of home care therapy is often denied once a child enters school and is no longer determined to be homebound.

Consider the following scenario: Twelve-year-old Johnny is a hemophiliac requiring daily physical therapy. Johnny's mother is an alcoholic and a prostitute. Johnny lives with his grandmother, but she is unable to follow through with the recommended daily exercises and other therapeutic interventions. Therefore, arrangements were made for the physical therapist to visit Johnny in school. School personnel refused this arrangement because of increased liability exposure. Medicaid, stating that Johnny was no longer homebound, denied ongoing home visits by the therapist. Outpatient physical therapy was not an option due to limited transportation and the unstable family situation. The child suffers as a result of inadequate policies and lack of services, availability, and coordination.

Other common services needed by medically fragile children in school include speech therapy, occupational therapy, psychologically-oriented therapies, transportation, environmental adaptations, and vocational counseling. These are considered "related services" under P.L. 94-142. They are not guaranteed services for the technology dependent child not requiring special education.

It is clear that new policies must be developed to meet the special educational needs of the medically fragile child and the family. Without such support, children are placed in the center of the growing conflict among educational facilities, health care providers, and families as to what services are necessary and who is financially responsible for their provision.

E. Paraprofessional Care

Traditionally, home care involves the provision of nursing, physical therapy, speech therapy, occupational therapy, and social work services. Rarely do we consider the involvement of the paraprofessional when we talk of pediatric home care. Yet, as crucial as the traditional medical services are, they alone cannot provide necessary

solutions to the complex and specialized needs that challenge providers of pediatric home care. Although the involvement of the paraprofessional in the provision of home care to medically fragile children fosters comprehensive care, public policies do not assure such involvement. Our view of home care is commonly split between the "medical" and "social" aspects of care. Medicaid and insurance coverage often support medical services alone. Placing the skilled, medical care at the top in terms of priority and importance, and relegating the unskilled, social services to the bottom replicates institutional structures in the home and contradicts the philosophy behind caring for our medically fragile children at home.

The advantages of including the paraprofessional in caring for high risk children are particularly well demonstrated in a High Risk Infant Project implemeted in Pinellas County, Florida. Funded by a collaborative effort of the March of Dimes, Juvenile Welfare Board of Pinellas County, and Family Service Centers of Pinellas County, the project involved specialized training for the homemaker-home health aide in the area of caring for high risk infants and their families.

For example, a full-term baby was born with extensive brain damage from a high fever contracted by the mother early in pregnancy. The mother was only 19, spoke only Spanish, and was in the United States only four months. The father worked hard, but was ashamed of the baby and withdrew from personal involvement iwth him. The family had numerous financial problems and could not afford its own pediatrician for the baby's special needs. The baby was sent home with a feeding tube surgically inserted into his stomach, an apnea monitor, and seizure medication. A Spanish-speaking homemaker interpreted for the mother in the hospital and afterward for all contacts with other agencies and for outpatient clinic visits. She assisted the mother in applying for Social Security Disability benefits for the baby and WIC coupons for formula. The family was referred by the supervisor for the homebound infant stimulation program. This homemaker also helped to get marriage counseling for the couple through their church, and enrolled the mother in English classes. The homemaker eventually helped the mother to arrange for temporary placement of her baby in medical foster care to obtain necessary relief because of the severity of the baby's condition.

Without the homemaker service, this young mother would have faced challenges beyond her ability to conquer, resulting in repeated hospitalizations for the baby and potential devastation of the family. Availability of specially trained paraprofessionals can have significant impact on a child's need for rehospitalization and a family's adjustment to a stressful situation. Consequently, the costs of caring for medically fragile children can be minimized given the availability of supportive home services.

F. Hospice

Hospice care is another critical, yet neglected, component of a comprehensive pediatric home care program. All of the problems faced by the family of a chronically ill child can appear magnified in the context of a terminal prognosis because, against the enormous array of stresses they already bear, the family members must come to grips with impending death and separation.

Hospice is a philosophy, an interdisciplinary approach which emphasizes palliative and supportive services for the terminally ill child and his/her family. It has been largely overlooked in the context of the child, perhaps because of the need to repress from our collective consciousness this most distorted version of the ideal. Yet the void which hospice should fill exists in the pediatric community, and indeed may be

increasing as the AIDS epidemic reaches this population group. Moreover, the circumstances of death and dying in this quarter may differ significantly from those involving adult patients. Different support structures, from pain management through bereavement counseling, may be required. Without them, a family may be thoroughly unable to cope with the loss they must face.

For whatever reason, this nation has been slow to focus on pediatric hospice care. Only 183 pediatric hospice units exist in the entire United States. A few are independent pediatric programs; some are affiliated with pediatric and children's hospitals. Most, though, are expansions of regular hospice programs to include children and adolescents.

Funding for pediatric hospice care is often non-existent. Many private insurance policies make no provision for it. Only three states, New York, California, and Florida, have adopted a Medicaid hospice benefit. Three other states, New Mexico, Illinois, and Indiana, are considering adding it, but of course participation is limited to Medicaid-eligible children. Common decency demands a re-evaluatin of any national health policy which excludes this component of care.

6. Case Management

Coordinated case management, like home care itself, serves a variety of purposes. It reduces the stress load on the members of the pediatric patient's family, who may direct their energies away from the exhausting and often frustrating task of seeking out medical, social, and other services and toward the principal task of caring for the sick or disabled child. In addition, preliminary studies indicate that case management systems help to reduce overall expense.

The REACH project in Florida, with a grant from the Robert Wood Johnson Foundation and the Florida Medicaid program, trained nurses to serve as case managers for cases involving chronically ill children. Through effective utilization of services, the case managers decreased outpatient procedures and rehospitalizations with a resultant 17% reduction in gross health costs after payment of the case managers themselves. Thus, the project demonstrated the cost effectiveness of a case management system, as well as positive care aspects.

IX. SUMMARY AND CONCLUSIONS

Two years ago, former Senator Frank E. Moss, Chairman of the Board of Trustees of the Foundation for Hospice and Homecare, announced that the Foundation would begin "a thorough examination of the problems of chronically ill children" through its public policy arm, the Caring Institute.

In the course of this study, the staff had access to all books and references in the National Library of Medicine. Questionnaires were sent out to physicians, nurses, home health agencies, and other experts. Dozens of families were interviewed, some of them on video tape.

The families selected for interview were broadly representative. The interviews themselves were conducted in ten states: Arizona, California, Connecticut, the District of Columbia, Illinois, Maryland, Michigan, New York, Pennsylvania, and Virginia. These ten states account for roughly fifty percent of all national expenditures for health care.

> The primary conclusion of this report is that the United States has failed to develop a national policy with respect to its growing population of chronically ill or severely disabled children. This failure in public policy means that thousands, of children are kept in institutions when they could be at home.
>
> There are several important ramifications of this fact. First, the children are deprived of their freedom and the opportunity to grow and develop to the full extent of their potential. Second, families are pulled apart and subjected to incredible pressure. Third, society, the families, and private health insurance companies pay two to five times more to keep the children in an institution than they would if the children were at home. Fourth, society is deprived of the gifts and contributions of these children who are kept in a dependent state instead of being encouraged to become active, independent, and contributing members of the community.

Following are other major conclusions reached in the context of this report:

1. There are approximately two million children in the United States who suffer from severe chronic illness. Many of these children are kept in hospital intensive care units or other institutions. Another ten million children are afflicted with some degree of chronic health impairment which inhibits daily functioning. Accident victims must also be added to the list. It is estimated, therefore, that from one to ten percent of the nation's children suffer from chronic problems of a moderate to severe nature.

2. The above figures are significant because a small minority of this nation's children currently account for approximately forty percent of all pediatric inpatient days in hospitals in the United States. Thus, while their numbers in one sense may seem small, chronically ill children account for an inordinate amount of the nation's health care resources.

3. A high percentage of the nation's chronically ill children were born premature. Modern technology has made it possible to save lives of infants who weigh two pounds or less. A few years ago a rough rule in medical science was that children were not likely to survive unless they weighed more than three pounds.

A second large category is made up of children who were carried full term, but who are born with birth defects.

4. Most of the children fall into eleven categories of so-called "marker" diseases, including leukemia, cystic fibrosis, congenital heart disease, spina bifida, asthma, hemophilia, chronic kidney disease, juvenile diabetes, muscular dystrophy, cleft palate, and sickle cell anemia. A small but rapidly growing number of children are victims of AIDS.

5. The primary emotions of parents whose child suffers from birth defects or other anomalies are fear and frustration. The words most commonly used by parents to describe their reaction were: "We were terrified."

6. Most families want to have their children at home with them. Contrary to mythology, most families do not abandon their children if they are born with anomalies. They accept them and want to have them at home as part of the family unit.

7. Physicians are in agreement that it is possible to manage the care of most children at home--even complex cases involving multiple disabilities.

8. Physicians interviewed were in general agreement as to the criteria which must be met before a child can be discharged from an institution into a home care setting. First, the child must be medically stable. Second, the transfer to the home must offer the child an improved quality of life. Third, the transfer to the home setting must be an acceptable risk. The risks must be small enough to be offset by the advantages of having the child at home. Fourth, the family must be willing and able to take on most, if not all, of the child's care. Fifth, there must be adequate community support available. The most important factor in all of the above is number four. As one doctor puts it, "What you really need is some people who are committed."

9. The major obstacle which stands in the way of bringing chronically ill children home is lack of funding. Either no funding exists, or ironically, there is a bias in government and private health insurance programs in favor of institutionalization. What this means is that families face a Hobson's choice. They can either leave the child in the hospital where care will be reimbursed, or bring the child home where there is little or no reimbursement available.

10. There are several programs which purport to provide financial assistance for chronically ill children, the most significant being Medicare, Medicaid, Crippled Children's Services, and CHAMPUS. Significant obstacles prevent most children from qualifying for any of these programs, and even for those who successfully navigate the maze, there is little money available for home care. The Medicare program, for example, is limited to the elderly and the disabled. After the child has been disabled in Medicare's terms for more than two years, the child might qualify for Medicare benefits. Even so, only three percent of Medicare's payments go for home care, and a tiny fraction of that is paid for pediatric home care. The basic problem is that Medicare covers only very limited kinds of home care and is focused on acute illness. It does not provide payment for chronic conditions other than end-stage renal disease which exist over the long-term.

Medicaid is a program which is only available to the poor. Income and assets limits of this federal-state grant-in-aid program are set by the states at comparatively low levels. In order to qualify, most families have to "spend down" their assets, and sell off their home and possessions, using this money to

provide care. Medicaid might then provide coverage if their income level isn't much over $5,000 a year. One way around this roadblock is the home and community-based waiver, in which the normal deeming requirements are set aside. This is not a solution to the funding problem because it allows a relative handful of children to obtain coverage on an "exceptions basis." Overall, however, Medicaid's home care benefit is only about one percent of the entire program. It is not really even a national program since over sixty percent of Medicaid's home care funds are expended in one state, New York. Moreover, most of the funds are spent on older Americans. No one has any precise figures, but pediatric home care probably accounts for only a fraction of the limited $750 million in Medicaid home health dollars.

The CHAMPUS program provides health care benefits to members of the armed services and their dependents. The program provides some payment for the problems of chronically ill children as long as they are hospitalized. However, there is a monthly limit of $1,888 for any child cared for at home.

11. Most major medical plans sold by commercial insurers contain a bias towards institutionalization and provide inadequate protection for technology dependent children. It is not unusual for some of these special children to spend up to the lifetime limit of their insurance policies in the first year of their lives if they are hospitalized continuously. Often this means that these children will no longer be covered by any insurance; they will be disqualified because of their so-called "pre-existing conditions." Even when there is coverage under the policy, it is often difficult to collect. One parent said, "It is like banging your head against the wall." To the extent that insurance provides coverage, the price for that coverage is to retain the child in the hospital. Coverage for home care, even though it is a fraction of the cost of comparable care in a hospital, is generally not accepted. One major exception: Aetna Life and Casualty provides excellent coverage under a program they call Individual Case Management.

12. Thousands of children live in hospitals and institutions not because they need to be there, but because that is the only place where reimbursement is available for their care. Prolonged hospital stays pose significant problems, including the following: (1) development of the children is hindered so that they are, in the opinion of experts, "years behind their peers;" (2) bonding between parents and their child is inhibited when the child is the responsibility of the hospital; (3) having a chronically ill child in the hospital produces tremendous stress, more so than having the child at home, and can have the effect of pushing the family apart; (4) a hospital environment is a regulated, regimented existence, depriving the child of his or her freedom and of the opportunity to enjoy the highest quality of life; (5) in some instances, a hospital environment can be dangerous. The risks of infection for ventilator-dependent children are much greater in the hospital than they are at home.

13. Home care has significant advantages for most chronically ill children. Among these advantages, according to experts, are the following: (1) the quality of the care rendered by trained parents augmented by professional nurses is just as good, if not better, than what is available in the hospital; (2) the home offers a more positive environment, promoting both improvements in the child's mental attitude and in his or her medical condition; (3) having the chronically ill child at home can reduce the significant levels of stress which parents face in these circumstances; (4) home care aids in the child's development. One physician said, "They just blossom;" (5) home care is generally less expensive, often costing only ten to twenty-five percent of comparable care in a hospital; (6) home care offers children freedom and preserves their right to treatment in the least

restrictive environment; (7) home care helps keep families together; (8) home care helps provide children with the highest quality of life.

14. Parents need training and support if they are to successfully take on the care of their chronically ill or severely disabled children at home. Some children have to be watched twenty-four hours a day for fear that they will not continue breathing. Without help which enables the parents to get some sleep, the care of the child for more than a day or so would be impossible. If properly trained, parents can assume many of the duties which were performed for the child in the hospital, but not all of them. Some procedures must be performed only by licensed nurses in conformity with state law and the best interests of the child.

15. Chronically ill children cared for in home care programs need continuing follow-up care by physicians on a regular basis, and under some circumstances they need to be readmitted to the hospital. Unfortunately, some families find that once they bring their children home, it is hard to get them back into the hospital when that is what is needed. This appears to be a function of third party reimbursement, which is both limited and inflexible, as noted above.

16. Service coordination, or case management, is a very important part of a successful pediatric home care program. What this means is that someone must accept responsibility for coordinating all the care and services that the child needs. One parent described caring for one of these youngsters as "kind of a three ring circus." Another said that it was like trying to replicate all divisions of the hospital in your home. Parents need the assistance of a social worker or other health professional who can help them get the supplies and services that are needed by the child. The help is needed in part because the current system is so fragmented and disorganized that it takes skilled hands and experience to navigate through the maze to reach the goal of quality home care.

17. Even after parents have been successful in bringing their children home, they live with dangerously high levels of stress. The degree of stress they face increases directly with the severity of the child's condition and inversely with the amount of support that is available to them. Many families live on a daily basis with the fear that their child may stop breathing and die unless they are able to resuscitate him or her. Parents live always on the alert, their lives revolving around the child, a fact which produces a high degree of stress.

18. There is no scientific study, but the best evidence suggests that having a chronically ill child generally brings a husband and wife closer together. The variable seems to be the solidarity of the marriage in the first place. Stronger marriages seem to benefit, while the pressure seems to shatter weaker ones. The above opinion is complicated by the fact that fifty percent of all American marriages end in divorce, and it is really impossible to sort out all of the causes for the dissolution, let alone to point to one factor as the proximate cause of the termination.

19. Having a chronically ill or severely disabled child in the family can have profound effects on other siblings. Older children normally feel rejection and suffer a sense of loss when a new baby is brought into the family. This sense of rejection is accelerated when the child is chronically ill and totally consumes the attention of the parents. The effects on other children are highly variable, but it is not unusual to have them withdraw, become depressed, fake illnesses of their own, or indulge in socially unacceptable behavior in order to get attention. In other instances, the older children understand and tolerate the situation, often pitching in to help the parents with the care of the new infant. In the home care

setting, there is no question but that the chronically ill child benefits from having the company, the love, and support of his or her siblings.

20. Having a chronically ill child puts a severe strain on friendships. The consensus among family members is that having an ill child over a long term is damaging to outside relationships. Parents said that they simply did not have the time and the energy which was needed to sustain them. "You can't really share something this intense and complicated," said one family member. Families of technology dependent children make new friends in networking with others who share their situation. Such support groups made up of parents of chronically ill children are extremely important.

21. Families are in agreement that despite all the pressures, having and caring for one of these special and fragile children is the highlight of their lives. Asked what was their happiest moments, parents were unanimous: bringing the child out of the hospital to be cared for at home.

22. The most difficult moments in the lives of these families generally involve a health crisis where the child hovers on the edge of death. Equally difficult moments are trying to find funding for home care and wrestling with insurance companies who should pay under the terms of their contract, but who do not.

23. Once a child has been cared for by his family in the home setting, rehospitalization of the child can have highly negative effects. The children may regress in their development, becoming withdrawn and depressed. Speaking of one such child as an illustration, one physician said: "It would be disasterous. It would create a depressed child who in fact may even withdraw from the world."

24. Families and medical professionals alike are in strong agreement on the need for respite care to maintain the success of any pediatric home care program. Families need a break from the pressure. Respite can be in the form of having someone else watch the child during eight hours of the night; otherwise, one parent will have to stay up with the child. Parents need some time to themselves, an opportunity to run errands, to take care of their own needs, or just to rest. A short respite will allow most families the chance to gather the strength they need to continue to provide safe care for their youngster.

25. Children who are dependent upon modern technology need education just as much as other children. In fact, the need may be even greater depending on how much of his or her formative years are spent in the hospital. Parents must be taught how to help their children, and when the children reach school age, provision must be made by public schools for their education.

26. Health care professionals who deal with chronically ill children need special training. Schools of medicine and nursing should place greater emphasis on the special needs of technology dependent children and the possibilities for home care. The simple fact is that many nurses who were educated ten, fifteen, or even five years ago do not have an adequate understanding of the existing technology. In most instances, the quality of care has been good, but in some instances it has not been acceptable.

27. One of the primary conclusions of this report relates to the need to educate the American public. Relatively few people understand the extent of the technological revolution. Only about forty percent of the American public knows about home care as an alternative to keeping chronically ill or severely disabled children in the hospital. There is a need to inform affected families in particular,

since most of them have nowhere to turn when their child is born with long-term health care problems.

28. There is a strong need for pediatric hospice programs. Hospice involves a coordinated program of palliative and supportive services to the person and his or her family. Unfortunately, there are few entities which provide hospice services for children, and there is no reimbursement for it under public programs. Given the fact that the number of these fragile youngsters will continue to increase over time and the fact that many of them will die, a national pediatric hospice program of some sort would be an excellent idea.

29. Pediatric home care is significantly more cost effective than comparable hospital care. The main reasons why children should be cared for at home are: (a) it is better for the child; (b) it is better for the family; and (c) it keeps families together. The fact that home care is more cost effective than care in a hospital, sometimes by a margin of ten to one, is an added bonus. However, the fact, that pediatric home care is more costeffective tends to point up the failure in public policy. Public policy has not kept pace with the changes in technology.

30. Pediatric home care benefits very dramatically from state to state. As a result, parents may be forced to uproot the family and move to a different jurisdiction in order to secure adequate funding for their chronically ill or severely disabled child.

31. Modern technology, which has saved the lives of thousands of children who previously would have died, may itself provide the answer to many of the dilemmas posed by the survival of these children. The technology has been miniaturized and made portable so that it can be available at home and, indeed, can follow along with the child wherever he or she might choose to go. Much of this technology was developed as a spinoff of the U.S. space program, where it was necessary to be able to monitor the health and vital signs of astronauts thousands of miles from the earth. This technology in the hands of competent medical and nursing professionals and adequately trained family members promises not only to lengthen, but also to enrich the quality of life for millions of American children in the years to come. All that is necessary is for third party payors, including the government, to agree to pay for its use in the home as well as in the hospital.

32. When asked what advice they would have for other parents in similar circumstances, the families of technology dependent children were unanimous. Sandy Reckeweg spoke for all when she said:

> "Fight for home care 100 percent because it is very well worth the effort; it is worth every ounce of energy that you put into these kids, to see them grow and develop to their fullest potential."

THE NEED FOR A NATIONAL POLICY ON LONG-TERM CARE CENTERED ON ASSISTING PATIENTS TO BE CARED FOR AT HOME

The federal government's lack of response to the needs of chronically ill children and others who require catastrophic long-term care is a public policy failure of enormous proportions. Long-term care has too often been misunderstood to mean the kind of custodial care associated with nursing homes. In reality, it is related to chronic illnesses; illnesses that are often incurable and that always continue over a protracted period of time.

These are truly catastrophic health conditions. They destroy families and can consume a lifetime's savings in a few short years. The need for long-term care has been documented repeatedly through the years in the context of the aging. But as this report details, that great need is not limited to the elderly.

The Caring Institute of the Foundation for Hospice and Homecare recommends and endorses the development of a national policy with respect to long-term care. This policy should address the needs of the young and old alike. The essential elements of this policy are that it be comprehensive, ensure family solidarity, and provide the care necessary in the least restrictive environment possible.

PRINCIPAL RECOMMENDATIONS

CRIPPLED CHILDREN'S SERVICES

The principal flaw in our current national health policy as it impacts on chronically ill or severely disabled children is the lack of a comprehensive program of care at home. As discussed below, Medicare is largely inapplicable to this pediatric population. Medicaid, the major source of government dollars, suffers both from inadequate coverage and from fragmentation at the state level.

The inadequacy of coverage is easily documented. The total outlays of the Medicaid program in 1985 were about $38 billion. The lion's share of this money -- more than forty percent of it -- went to pay for nursing home care. Funding to help care for patients in their own homes, by contract, amounted to only $1.1 billion, or just slightly less than three percent of the entire program. And of course, not all of even this minimal allotment went to serve chronically ill children.

Obviously, Medicaid suffers from an institutional bias; this, despite the fact that evidence from the U.S. General Accounting Office and other sources indicate that a significant proportion of institutional patients (on the order of twenty-five to forty percent) do not belong in a nursing home and could be cared for at home. What is more significant is that most of the payments for home care under Medicaid were in one state, New York. That state's "Nursing Homes Without Walls" program, which provides the home care alternative to carefully screened patients who would otherwise be in nursing homes, has enabled New York to save an estimated fifty percent of the expenditures it would have made for nursing home care.

When the New York program is removed from the equation, the resources currently being made available to home care patients generally and pediatric home care patients in particular are indeed miniscule. In addition, because many of the coverage and eligibility criteria for pediatric home care services are currently left to the states, there is wide variation in availability. In at least one state, Arizona, parents are even faced with the possibility of having to make their child a ward of the state in order to secure coverage.

For these reasons, it is recommended that The Crippled Children's Services component of Title V of the Social Security Act, the Maternal and Child Health Services Block Grant, be expanded to provide a complete and organized program focusing on the pediatric home health care alternative. While states would maintain some responsibility for directing available funds to appropriate recipients and for overseeing the provision of services, the federal government should act to establish uniform eligibility standards. The federal government should also mandate covered medical and support services, including adequate respite care, to enable the families of medically fragile children to cope with the stress associated with their caregiver roles.

CHAMPUS

CHAMPUS is the federal program which pays for health care for servicemen and their families. Of all the public programs, CHAMPUS received the worst marks from families of chronically ill children. Its limitation of $1,000 a month for home care is totally inadequate to meet the needs of technology dependent children. Effectively, this forces more costly and less humane institutionalization.

Congress could provide a significant benefit to the members of the armed forces and their dependents and recoup significant savings by revising this antiquated policy.

HOSPICE

The Congress should enact a national program which provides hospice care for children. Hospice coverage is presently provided for the elderly under Medicare, but no counterpart for children exists.

OTHER RECOMMENDATIONS

MEDICARE

This report focuses on the pediatric population, and its principal recommendations are, therefore, addressed to those programs which serve the vast majority of chronically ill or severely disabled children. However, there is a corollary question which underlies this entire issue: as technology extends the lives of these medically fragile individuals, what provisions are being made to ensure their continued well-being when they reach adulthood?

The answer to this question turns on a reexamination of Medicare. Medicare's definition of disability is unduly restrictive in its present application. As a result, virtually no children under the age of eighteen qualify for benefits. Benefits for those over age eighteen are also limited to short term, or so-called acute, care. Medicare

coverage is further restricted by terms which limit access to home care to those who are in need of intensive services (skilled nursing care) and yet not ill to the point where they require assistance on a more than intermittent basis. Benefits are still further limited in that they are only available to those confined to their own homes and to those whose care is deemed reasonable and necessary for particular conditions.

It is recommended that the Medicare benefit be streamlined so that it provides coverage for home care services for chronically ill individuals age eighteen and over. The elimination of the impediments described above would be a major step forward in the enactment of catastrophic health protections for the elderly. It would also prevent the needless institutionalization of thousands of children and adults.

As with expansion of the home care program for chronically ill children under Title V, any comprehensive program under Medicare must include respite care services.

PRIVATE HEALTH INSURANCE

1. The Congress should enact legislation which provides private health insurance companies with favorable tax treatment for reserves assigned to comprehensive private health insurance plans that provide exemplary home care coverage for chronically ill children.

2. Out of self-interest and concern for the bottom line if nothing more, private health insurance companies should examine their comprehensive health insurance plans and eliminate any existing institutional bias. The focus of coverage should be the care that is needed, not the location of the care.

3. Similarly, union and employer-based health insurance plans should be purged of institutional bias, and expanded to cover home care services.

4. At a minimum, insurance companies should be encouraged to follow the example of Aetna Life and Casualty and create programs similar to that company's Individual Case Management program.

EDUCATING MEDICAL PROFESSIONALS

1. The federal government should increase the funding available for training of medical personnel in the special needs of chronically ill children, facilitating their care at home.

2. Schools of medicine and nursing should increase their educational programs at both the undergraduate and the graduate level to place greater emphasis on the needs of chronically ill children. These programs must give medical professionals a thorough grounding in the developing technology and the special pressures and problems of families who struggle to care for technology dependent children.

3. Continuing education programs should also be established to help update the practitioners after their graduation.

THE NEED TO EDUCATE THE PUBLIC

The families of chronically ill children indicated that they learned about home care and other potential services for their children almost entirely by rumor and trial and error. The most frequent comment made by the parents during the interviews conducted by the Caring Institute was, "I just picked up the phone and called everyone in the phone book." There is a paucity of information advising parents what to do or where to go for help. In particular, there is scant information available about the benefits and limitations in existing public programs.

It is recommended, therefore, that the Department of Health and Human Services develop a public information campaign and other outreach mechanisms to help educate the public about existing programs and about how to care for their technology dependent child.

RESEARCH

Given the steady increase in the number and percentages of chronically ill children, the federal government should increase research, design and identify the care and possible cure for the eleven so-called marker diseases identified in Chapter II of this report.

EDUCATIONAL PROGRAMS

The federal government should increase funding for programs which provide educational opportunities for chronically ill or technology dependent children.

PREPARED STATEMENT OF THE ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

The Association of Maternal and Child Health Programs is the organization of state and territorial public health programs which administer the Maternal and Child Health Services Block Grant under Title V of the Social Security Act. We are pleased to have this opportunity to articulate our concern about the plight of children and youth with catastrophic illness, injury or disability whose families lack adequate resources to provide them necessary health care and services.

Statement of the problem

A growing proportion of American children live in families who do not have health insurance, public or private, to assure that they will receive necessary care when confronted by sudden illness or injury. As the severity of the health condition increases, or its duration becomes protracted, high care costs are likely to precipitate family economic distress. Especially vulnerable are families with low incomes who do not qualify for most public programs (particularly Medicaid), but whose employers do not provide any health insurance as an employment benefit. These families typically cannot afford routine medical care, let alone the expense of hospitalization or extended special care.

Expansion of Medicaid eligibility and benefits would certainly extend care to any underserved children and their families. Tens of thousands of additional families, however, would remain uncovered by any current public or private program. Low-income families who could not qualify for Medicaid would also be unlikely to afford the premiums necessary to purchase insurance. Such families are victims in a complex health care system that increasingly allocates its services to those individuals who have the resources to pay provider charges. Not only are such families unable to purchase services, but they generally lack access to professionals or agencies that can assist them in coordinating or managing available services. The absence of care coordination or case management has several adverse consequences, including the provision of sources that are fragmented, clinically inappropriate, or unnecessarily expensive.

Resolution of the problem

Children and youth should have access to necessary health care and services. There is a public responsibility to assure that care is provided. That responsibility can be exercised through two mechanisms:

- improved financing of care for children and youth with chronic health conditions;
- funded care coordination and case management for these children and youth.

We urge Congress to enact legislation to address these needs using two complementary strategies.

- Assurance of high-quality services through care coordination and case management.

  Children with catastrophic conditions require complex services usually from multiple professionals working in numerous facilities and agencies. The coordination of care can reduce or eliminate fragmentation, inappropriate care and unnecessary expense.

  We propose that state Title V programs be charged with care coordination responsibilities, including establishment of standards, in any federal program for children with catastrophic health conditions. The state programs in most cases already have mechanisms in place for these functions and are familiar with the diverse resources required by the children.

- Initiation of a children's catastrophic illness financing program.

  Additional public resources are needed to purchase care and services, or permit families to purchase insurance from available commercial insurers or through state-mandated high-risk insurance pools. This option should be adopted in addition to currently proposed

expansions of the Medicaid program.
We propose that state Title V programs be the manager of a children's catastrophic illness program. The state programs for children with special health care needs (formerly known as crippled children's services programs) have extensive experience in providing services to low-income families whose children have chronic illness or disability. The Maternal and Child Health Services Block Grant is the only federal legislation with the specific task of serving the health care needs of this population.

We would look forward to working toward a solution enabled by the enactment of legislation.

Thank you.

PREPARED STATEMENT OF THE HONORABLE TONY COELHO, A MEMBER OF CONGRESS FROM THE STATE OF CALIFORNIA

The Select Committee on Children, Youth, and Families and the Select Committee on Aging, especially the respective Chairmen George Miller and Edward Roybal, are to be congratulated for holding this joint hearing on expansion of the Administration's proposed catastrophic health plan. The recent focus on the catastrophic health care needs of America's elderly has also served to highlight the health care needs of our nation's youth. I am happy to see that these two Select Committees have so appropriately siezed this opportunity to bring before the public the pressing need of examining the health needs of all Americans, young and old.

Both Committees today will hear from witnesses who will describe the unnecessary pain that face children and their families when they lack the insurance necessary to pay the staggering costs of needed care. There is though, one situation which the Committees will not here about. This is the situation of children with disabilities and medical conditions who are not covered by health insurance carriers solely because they are adopted; too often, insurance providers refuse to cover these conditions of an adopted child because they are termed "pre-existing". In other words, because a child has a disability or medical condition prior to being adopted, the insurance carrier of the adoptive parents will not cover the child when he or she is adopted. The result is that some children do not get adopted because would-be parents can not afford the potential medical bills or that adoptive families live under the spectre of financial ruin. This is true despite laws in every state but one (and that state has case law to the same effect) stating that adopted children are to be treated identically as biological children. This is, pure and simple, discrimination on the part of health insurance providers towards adopted children and adoptive families. Thus, the catastrophic health needs, and even the not so catastrophic health needs, of one segment of our youth population, those who are adopted, could be adequately met through the end of this discrimination.

As an adoptive parent and one who has a disability, epilepsy, I found this to be terribly disturbing. As a result, I have introduced House

Concurrent Resolution 43. This Resolution would express the sense of the Congress that this discrimination should end and would urge states to pass laws mandating that adopted children be treated fairly in health insurance contracts. Many organizations, including the Children's Task Force of the Consortium for Citizens with Developmental Disabilities, a large group of national organizations dedicated to issues regarding disabilities, and the National Committee for Adoption have endorsed this Resolution.

Allow me to share some more of the background on this issue and the effect of this type of discrimination. Denying health insurance coverage to adopted children because of "pre-existing" conditions costs children, costs families, and costs tax payers. Children may not be adopted solely because of this problem. In one recent case that came to my attention, a girl was born with cerebral palsy. She immediately became available for adoption and several families expressed interest in adopting her. All decided not to adopt this child, however, when they learned that their health insurance would not cover any of the girl's medical care related to the cerebral palsy. At last word, this little girl, who otherwise would be very "adoptable", was still not adopted and was still sitting in foster care. In another case, that we heard of during hearings before the Congressional Coalition on Adoption last April, a baby was born prematurely and showed a brain mass on a cat-scan several days after birth. While the prospective parents wanted to proceed with the adoption, their insurance company refused to cover any of the expenses on the grounds that it was a "pre-existent" condition so the adoption disrupted.

While Medicaid is available for many special needs children who are adopted, for many others it is not available. Many special needs children who are not eligible for Federal adoption assistance under Title IV-E of the Social Security Act do not receive any Medicaid assistance. As the data on adoption and foster care in this country is lacking, we do not know how many children this is, but it is certainly considerable. For example, in the approximately half of all the states that do not have AFDC-Unemployed Parent eligibility, adopted children whose biological families were composed of poor, two-parent families may not be eligible for Medicaid. These children may not be covered by a State medical assistance program either. Add to this the children with some sort of medical disability who are not in the state child welfare system, but rather who are placed by private agencies, and the number of children hurt by this discrimination grows even greater. For

those children who are eligible for Medicaid, private health insurance may also be necessary as, depending on the state, many needed services, such as out-patient psychotherapy for a child who had been in foster care for many years, may not be covered by Medicaid. And many service providers do not accept Medicaid.

By treating adopted children the same as biological children for the purpose of health insurance, we will be removing a major barrier to adoption. At the same time, we will be alleviating the catastrophic health insurance needs of one segment of our youth. I urge all states to pass laws such as that passed by Minnesota and a handful of other states that require that insurance companies treat all children fairly -- whether adopted or not. And I urge all of my colleagues in the House to join me by co-sponsoring House Concurrent Resolution 43.

INSURANCE COVERAGE FOR DEVELOPMENTALLY DISABLED CHILDREN

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Prepared at the invitation of
the United States House of Representatives
Select Committee on Children, Youth, and Families

6 April 1987

Acknowledgements: This study was made possible through the support of the Division of Maternal and Child Health, the Administration on Developmental Disabilities and the National Institute of Mental Health. From the beginning of the project the late Nathan Smith was unstintingly generous in investing his energies and in sharing his wisdom. In addition to expressing appreciation to our project officers, Aaron Favors, Constance McAlear, and Paul Widess, we wish to thank a far flung team: our advisory board members, our local project coordinators and Survey Research Associates of Baltimore. We extend special thanks to Harriet Fox, Martin Frankel, Holgar Hansen, Torsod Lunde, Margaret McManus, Paul Newacheck, Loretta O'Dell, Herbert Simmel, Victor Tegtsi, Daniel Walden, Robert Wright and Pearl Zinner for sharing their expertise.

In 1986 the parents of a national sample of 326 children and young adults with severe or profound mental retardation and the parents of 309 children and young adults with autism provided information on the financing of their children's health care. The study includes children in residential placement as well as ones living at home. This preliminary report is part of a four year effort to document health care utilization, expenditures and sources of payment for three costly disabilities: autism, severe mental retardation, and hemophilia. Under consideration is a companion study of children who have spina bifida, or cystic fibrosis, or who are ventilator assisted. These six conditions have been selected for study because they are particularly costly and burdensome to families and because they occur so rarely that accurate data are not obtainable from standard national surveys.

THE PERCENTAGE OF DEVELOPMENTALLY DISABLED CHILDREN AND YOUNG ADULTS COVERED BY HEALTH INSURANCE COMPARED TO NATIONAL AVERAGES

	NONE	PRIVATE	PUBLIC	BOTH
DEVELOPMENTALLY DISABLED				
Autism n = 309	5-11 %	43-53 %	22-32 %	12-20 %
Severe and Profound Retardation n = 326	2-6	22-32	36-46	23-33

ALL AMERICAN CHILDREN

	4-10	53-66	12-24	11-19
Limited in Activity n = 249				
Not Limited in Activity n = 5996	7 %	69 %	14 %	8 %

"Limited in activity" means that the child's ill health prevents full participation in school or play. Each percentage is given as a range rather than as single number because these are the levels of accuracy that can be obtained from samples of this size and nature when generalising to the country as a whole.

The 1986 data on developmentally disabled youngsters from birth to age 24 are compared here with the most recent data on American children to age 21, the National Medical Care Expenditure Survey, 1980. Paul Newacheck provided the national analysis from his forthcoming article co-authored by Margaret McManus.

THE BROAD PATTERNS OF INSURANCE COVERAGE

- Autistic and severely retarded children and young adults are covered less well by private insurance than the average American child.
- These youngsters are substantially better covered by public programs than the average child.
- Coverage is not universal for these severely disabled children.

INADEQUACY OF PRIVATE HEALTH INSURANCE COVERAGE

- Between 18 and 28 percent of families where one parent is working full-time lack private insurance.
- White children are roughly twice as likely as minority group children to be covered by private insurance, even when taking into account whether a parent is working full time and whether income is above $15,000.
- Refusal of insurance or limitation of the kind that could be purchased was reported by parents of severely retarded children, projected to a national rate between 14 and 22 percent. Parents of autistic children experience refusals and limitations on purchase at half that rate.
- About 10% of the parents currently hold health insurance policies which they report as specifically excluding coverage for some or all of the child's care.

The research staff is now obtaining copies of the policies that cover the developmentally disabled children. Examination of these policies and of the claims records will show the variations in services which are actually covered.

Among Americans as a whole, young adults are the largest age group lacking health insurance coverage. Among the severely developmentally disabled, young adults are rarely covered by their parents' policies. The important difference is that severely retarded individuals aged 18 become categorically eligible for SSI and hence for Medicaid coverage. A 1985 change in the SSI regulations has made autistic adults categorically eligible as well.

COVERAGE BY MEDICAID AND SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS (ALSO KNOWN AS CCS, CRIPPLED CHILDREN'S SERVICES)

Public coverage generally includes the neediest among all these severely disabled children.

- Families with annual incomes under $15,000 are between 2.5 and 7 times more likely to have coverage than families with higher incomes.

- Single mothers are between 1.5 and 4 times more likely to have coverage than married couples.

- Severely and profoundly retarded children, many of whom have physical handicaps, are between 2.5 and 4.5 times more likely to have coverage than autistic children.

- Minority group status is not a factor in predicting whether or not a child has coverage from Medicaid or from Services for Children with Special Health Needs (CCS).

Inequalities exist.

- Seventy-five percent of the sample of developmentally disabled children in Fresno County, CA are covered by Medicaid or CCS, compared to 42% in Dallas and 50% in Jacksonville, FL.

POLICY RECOMMENDATIONS

If policies are addressed to improving private health insurance coverage for children, then insurance plans should be available to parents at reasonable prices that do not specifically exclude services for children with chronic conditions.

If policies are addressed to improving public health insurance, then national policies should reduce the discrepancies in eligibility among the states.

FUTURE REPORTS

These initial findings will be augmented with full reports on insurance coverage for children with hemophilia, autism and severe mental retardation as well as reports on: the use of health care services; variations in expenditures for medical and financial reasons; case management; family out-of-pocket expenditures; financial counseling; and marriage stability.

METHODOLOGY

In every step of the research we have first reviewed the methods used by the two leading health research agencies in the country, the National Center for Health Statistics and the National Center for Health Services Research, and then adapted their methods to the special populations of chronically ill children.

The 715 children in the study come from 11 sites which were drawn in a judgment sample from a national sampling frame composed of school districts that had been prepared by the National Center for Education Statistics and the Census Bureau. The frame was divided into levels based on four criteria relevant to health care utilization — family income, generosity of the state Medicaid systems, prevalence of employers which provide comprehensive health insurance packages, and availability of physicians. The sites are:

Birmingham and Jefferson County, AL
Detroit and Wayne County, MI
Duval (Jacksonville) County, FL
Fresno and Fresno County, CA
Des Moines and 11 surrounding counties, IA
Morris County, NJ
Suffolk County, NY
Dallas, TX

A project coordinator from each participating school district contacted a probability sample of eligible families. The overall consent rate was 55% for autism and 49% for mental retardation. Each participating family signed a consent form that permitted collection of retrospective data for the prior twelve months. Complete anonymity is maintained with regard to the use of the data in all reports. A paper reporting details of the sampling methods was presented at the 1986 national meeting of AAPOR, "You'll Find the Kids in School".

The questionnaire was adapted from the work of the National Center for Health Statistics in their 1980 National Medical Care Utilization,

Expenditure Survey (MEDIUES) and from the work of the National Health Services Research Center as they prepared for their 1987 National Medical Expenditure Survey (NMES). Survey Research Associates of Baltimore completed interviews with 97% of the parents with working telephone numbers. An indication of the overall quality of the data they obtained is that income data were missing for only five per cent of household members. To supplement family information, data are now being collected from ten types of providers and payers: CCS, Medicaid, private insurance, HMOs, hospital inpatient, outpatient, and emergency room billing, physician's in private practice, dentists, and usual sources of medical care.

The results reported in this study are given as a range rather than as point estimates because sampling error and non-sampling error prevent greater accuracy. A population weighting system based on urban/suburban residence and generosity of the state Medicaid system was used to weight the sample to represent metropolitan America.

Several logistic regressions were run to prepare this report. In a preliminary step, eight variables were run as an OLS regression to predict the likelihood that a child is covered by private insurance, including HMOs and CHAMPUS. These variables were influential in this order:

p < .0001
number of parents employed full-time

p < .001
being white

p < .01
being severely retarded rather than autistic
mother's level of education
two parent family
high income

p < .05
the less the severity of the condition as measured by age at diagnosis
the younger the child

In predicting that a child is covered either by Medicaid or Services for Children with Special Health Needs (CCS) the rank order of the importance of the variables is:

p < .0001
being older
having severe mental retardation rather than autism

p < .001
number of parents employed fulltime
poverty

p < .05
having a single mother
living in a state scoring the mean on a scale of Medicaid generosity

N.S.
minority group membership
level of the mother's education

The logistic regression on coverage by public insurance which was reported here included variables for the child's disability, family income, mother's marital status, and generosity of the state Medicaid program. Subsequent work on the issues concerning insurance coverage will test structural equation models using MGLS regression, logit, and probit.

STATEMENT OF ALBERTA MILLER - GRANDMOTHER OF DWIGHT MILLER
WASHINGTON, DC
March 23, 1987

My name is Alberta Miller. I am the mother of 4 children and 4 grandchildren. Until last August, I lived with 3 of my children and was supported financially by public assistance. Then, catastrophy hit my family.

My daughter Ann died after giving birth to her fourth child. She died from birth complications related to AIDS. After she died, I was left with the responsibility of caring for her children -- 2-year-old Dwight, 5-year-old Charles, 8-year-old James, and 9-year-old Terrell.

Dwight, the youngest child, was born with something called an "AIDS Related Complex." It is a form of AIDS virus. He can get infections easily and needs special care. And if necessary precautions are not taken, he may die.

They tell me there are about 400 children in the country like Dwight. Caring for these children is hard. People don't understand what a family goes through. They don't understand the kind of help we need, and are afraid of AIDS.

Last September, I got a homemaker to help me with the cooking, cleaning, and washing. The homemaker only stayed 2 weeks. She left because Dwight has AIDS. No one else will take her place.

Because I have my daughter's children to care for now, I've tried to rent a bigger house, but nobody wants to rent to me when they learn about Dwight.

Dwight has Medicaid. It pays for a nurse and social worker to come to our house. Medicaid also pays for some of his medications. But I have to pay for the special things that Dwight needs, like plastic bags, plastic gloves, forks and spoons, wash cloths and towels, tissue, and other medications. This costs about $40 extra each month. I also have to pay for transportation to the doctors, child care, and respite care. All of this comes to almost one fourth of my total income.

The hardest thing about taking care of a child who has been exposed to the AIDS virus is feeling alone. I can't tell all of my family and friends about Dwight because they don't understand. I worry about whether he will live. I worry about if he does live and goes to school, how will the teachers and the other students treat him?

Dwight is with me because I love him and want him. But if something happens to me, he could easily end up in an institution.

Thank you.

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March 24, 1987

Rep. George Miller
2228 Rayburn Bldg.-HOB
Washington, D.C. 20515

Dear Representative Miller:

I am writing to you in your capacity as Chairman of the Select Committee on Children, Families and Youth.

I have been an insurance broker, specializing in health insurance for over 13 years. In addition, I am an attorney. It is only because of this background that I was able to protect my family financially when my son became seriously ill.

My son has had a kidney problem for three years now, and recently suffered kidney failure. He will have a transplant later this year if all goes as planned. Fortunately, I have excellent medical insurance, and medicare will serve as a back-up. However, the result could have been very different.

I was contemplating a career change in the fall of 1986. However, I knew that if I left my position as Agent for Equitable Life, I would have to obtain new health insurance. The new plan would have a pre-existing condition clause, preventing coverage for my son for at least one year for the kidney condition (if he would be covered at all). Little did I know that his kidneys would fail in the first month of my new career.

Fearing this possibility, I stayed on as an Agent of Equitable, retaining my group benefits, while starting a law practice on the side. Thank heavens, or we would have lost most of our savings already (medicare does not pay any benefits for the first 30 days of dialysis).

In considering the alternatives facing me last fall, I thought Pennsylvania health insurance law might protect us. Pennsylvania requires that all group insurance plans written

in Pennsylvania offer excellent conversion privileges for people leaving group plans. However, my group coverage is part of a large group, probably self-insured, and written in New York State. New York requires similar conversion privileges for its citizens for plans written in New York. However, I am not a citizen of New York, and the plan was not written in Pennsylvania. So Equitable offered me a conversion that was quite literally not worth the paper on which it was written.

However, it is not clear to me that either law would have forced Equitable to offer me a conversion policy if my demographics were correct. Because the group plan is likely to be a self-insured plan, it is not technically insurance. Therefore, it falls under the ERISA umbrella as a self-insured welfare plan, and benefits from the exemption from State law enjoyed by such plans. The fact that Pennsylvania and New York require conversion options for certain group "insurance" plans may be entirely irrelevant for large, self-insured group plans.

Assuming that this fact is true, virtually all employees of major corporations in America face the potential trap of becoming uninsured if they or a dependent is seriously ill when their group coverage terminates. Of course, I have the medicare umbrella to fall back on for my son. But how many catastrophic illnesses do not qualify for medicare benefits? Most, I am sure! And, I was among the lucky. I knew what questions to ask, and how to protect myself. Most people do not find out until it is too late.

Now, I am not talking about people who are unproductive members of society. I am thinking of successful people who pay taxes, and want to get ahead in life. We have a medical reimbursement system that has a gaping loophole that needs plugging. Without a roadmap and considerable knowhow, even people who have done everything right can loose everything from a serious illness.

Even the new COBRA legislation is of no value for people in situations like mine. Consider what would happened if I resigned from Equitable after the COBRA

legislation became effective. My family would have been able to continue coverage until the earlier of the following: for a year and a half, or until I obtained new group insurance coverage for us, if sooner. What would have happened at the end of the year and a half? Or, what would have happened if I was able to get new group coverage. The extended benefit of the old Equitable plan would automatically terminate upon the happening of either event. And, there would be the pre-existing condition problem of the new coverage to deal with. Lastly, the whole scenario would have to be repeated again upon my son reaching an age at which he would no longer be a dependent of mine.

I cannot begin to tell you how many sleepless nights I suffered over this problem. For this reason alone, I did not terminate my Agent's contract with Equitable, and embark exclusively on the law career. Should I and others in the same situation be prisoners in this "free society"? How many others were not as "lucky" as me, and lost everything, because they did not know how to navigate this trecherous system? And, are we to be considered "lucky", because medicare starts so early for kidney dialysis? My son could have "only" suffered some complications of his illness instead of complete kidney failure. Medicare would be of no help in that case.

I hope I have made my point on this matter. I would be happy to review with your committee alternatives that I think offer reasonable solutions to this problem and others like it.

Thank you for holding hearings on this very important matter.

Sincerely,

ALAN J. MITTELMAN, J.D., CLU

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An Association Statement

March 15, 1987

CATASTROPHIC ILLNESS EXPENSE AND CHILDREN

The report of Secretary of Health and Human Services Otis R. Bowen, requested by the President, acknowledged that catastrophic illness expense touches all segments of society. The Secretary's specific legislative proposal now endorsed by President Reagan, is limited to the elderly. It would enhance Medicare's Part B to prevent annual out-of-pocket expense of more than $2000 for Medicare covered services.

For a family, a child's illness or injury can be just as catastrophic as that of a grandparent. To a family without resources to provide adequate care for a child, health care expenses are catastrophic. Although this happens primarily among families who are uninsured, underinsured, or uninsurable, no one is immune from illness expense of catastrophic proportions. High technology care now available where previously no treatment was possible, can bring with it high costs and the dilemma of payment to those whose resources are sufficient for routine and anticipated services.

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Defining "Catastrophic Illness Expense"

Although difficult to define precisely, there are several ways of thinking about catastrophic illness expense:

* A percent of disposable income spent out-of-pocket for health care, given as five or ten percent
* Total cost of treatment for a specific disease, such as the cost of treating cancer
* A set dollar amount below which no expense level is considered catastrophic, regardless of income. A percentage of income is added to that amount to establish a threshold for catastrophic expenses. For example -- $2200 plus five percent of income

The threshold of "catastrophe" is relative to those resources which can be dedicated to illness expense without severe and lasting effect on living standards or other essential needs. For the elderly, protecting against catastrophe often focuses on maintaining living standards or guarding static resources needed for future living expenses. A young family is more concerned with building for the future, saving for education, or progressing toward a higher living standard. Catastrophe in this case threatens the stability of the family's current economic status and achievement of future goals.

Financial catastrophe may have several levels. Where a family's resources are severely limited, even minor events will result in financial catastrophe. As available resources increase, the threshold of financial catastrophe also increases. Yet there is always the potential for a serious or lasting erosion of the family's standard of living.

Of course catastrophe is not simply a financial concept. The stress of a child's illness or injury places emotional and social burdens on the entire family. A parent may have to cease working, leading to a decreased family income during a period of increased resource needs, with resultant stress. Siblings suffer from loss of parental attention and deprivation from the economic sacrifices imposed, such as loss of savings for higher education. As a whole, the family suffers from disruption of a stable and predictable family life-style. These emotional and social stresses affect families of all economic levels, though those with more adequate means or other support systems will absorb the shock better than others.

Catastrophic illness expenses in the pediatric population may derive from one or more of three sets of circumstances:

* Acute care needs which are sudden and episodic in nature:
  - Approximately 220,000 premature babies are born each year; with intensive care nursery charges approximately $1,000/day, average hospital charges are over $35,000 for an immature infant
  - Heart surgery for a child may cost a family $22,000 for a hospital stay
  - Treatment for extensive burns may result in a hospital bill of $45,000
* Chronic care needs which are on-going, have a cumulative effect, and are likely to be coupled with spells of acute illness:
  - Comprehensive care for children with cystic fibrosis can cost a family $6,000 - $12,000 annually; intermittent hospitalizations may average over $7,000 per stay
  - Institutional care for a ventilator dependent child may amount to $350,000 annually

- Primary care needs which are catastrophic for those with no insurance or very limited resources, which prevent their being properly addressed:
  - Treatment for an episode of asthma may cost a family $600
  - Routine hospitalization may incur costs of $700/day

Catastrophic Illness Expense Impact on Population Segments

Catastrophic expenses can befall all segments of the population. The extent to which a family will be faced with hardship will be determined to a great extent by the resources it has available to meet the need. Since health insurance is a prime resource, the scope of the catastrophic illness expense problem can be examined better by grouping the population by extent of insurance protection:

- The uninsured, estimated to be some 35 million Americans who are without health insurance
- The underinsured, another 10 million who may have insurance part of the year, or who have very limited benefits
- The uninsurable, who, because of health status, cannot obtain health insurance at a price they can afford

The uninsured are people who are unemployed, or whose employment does not offer health benefits for employees and/or their children. Often these individuals are employed part-time or seasonally. Yet, 60 percent of the uninsured in America do work. Eight million of the uninsured are dependents of employed adults.

Some individuals, such as self-employed businessmen and farmers, do not qualify for group coverage and must depend on costly - often unaffordable - individual coverage for themselves and their families. Individual policies are apt to include clauses restricting coverage for specific diseases, exclusion of coverage for pre-existing conditions, and very high premiums.

Lack of insurance and other available resources for health care results in immediate barriers to access. Adults may lack access to basic primary and preventive care. Mothers may not have access to adequate prenatal care, resulting in severely impaired premature infants or failure-to-thrive infants. Such births may represent a relatively short-term crisis, perhaps three months of intensive care, or they may result in chronic disabilities requiring years of specialized care, frequently with episodes of acute needs.

Parents may lack resources to provide for a child's short-term acute episodes of illness, such as asthma and ear infections. Left untreated, acute episodes may lead to serious, chronic, and disabling conditions.

Even when resourced to meet basic needs, a family may lack adequate protection for treatment of chronic conditions, rehabilitation, or the special support needed between acute episodes of a chronic condition.

Institutionalization may be mandated, despite preferences for and appropriateness of home care, in order for the family to receive public support.

Medicaid and Catastrophic Illness Expense for the Poor

Medicaid, the federal/state health care program for the poor and the major public program for child health, does not provide adequate coverage. In 1983, children under age 18 accounted for 38 percent of the poverty population. AFDC

children were 44 percent of Medicaid recipients, but caused only 12 percent of Medicaid expenditures. In the same year, those over age 65 constituted 11 percent of the poverty population but were 16 percent of Medicaid recipients. In sum, the elderly, blind, and disabled accounted for 75 percent of Medicaid expenditures.

Medicaid is an inconsistent national resource. States have overly broad discretion in determining eligibility and services covered. The variability by state of Medicaid coverage makes the program inherently inequitable in its services, simply as a function of geography. For example, in 1984, eligibility income in Alabama was 17 percent of the federal poverty level, while in California it was 74 percent. In that year, the poverty level for a family of four was $10,200. Overall, the average eligibility income in 1984 was only 38 percent of the federal poverty level.

States also are authorized to impose limits on services, including mandated services, within established guidelines. For example, in 1984:

- fifteen states imposed limits on the number of inpatient hospital days per spell of illness, ranging from 10 to 45 days
- fifteen states limited coverage for specific procedures
- twelve states limited the number of outpatient hospital services/visits per year
- fifteen states required prior authorization for certain services or procedures; and
- six states limited psychiatric services

Where coverage is limited by scope of services or eligibility levels, care often is delivered by the provider without compensation, which may mean that the provider cannot adequately or consistently support comprehensive services for all those in need. Further, changes in the health care marketplace make it increasingly difficult to transfer the cost of care of those who cannot pay to those who can.

States have the option to provide a Medically Needy Program, in which individuals can become eligible for coverage based on the amount of their incurred medical expenses. However, to date only 34 states have adopted this option. Again, within the Medically Needy Program, states control eligibility through levels of projected income, allowable resources, and length of time during which persons must spend down their resources. Even the Medically Needy option is lacking, with eligibility on average reaching only 31 percent of the federal poverty level.

Families Above the Poverty Level

People who are "near poor" and "middle class" often are underinsured. The economy is increasingly service-based, with large numbers of unskilled or semi-skilled part-time employees. Between 1979 and 1984, 60 percent of newly created jobs paid less than $7000 annually. Employers are not required to provide benefits for employees, or their dependents. There is no substantial incentive, such as a tax benefit, to encourage employees to select comprehensive health coverage for their children.

While more recent aggregate data are not available, the 1977 National Medical Care Expenditures Survey (NMCES) data show:

- Sixteen percent of poor children are always uninsured, despite the head of household being employed

- Only 70 percent of all children under age 18 are covered by private insurance all year
- Of those children with private health insurance, only 83 percent have major medical coverage, and less than ten percent have unlimited coverage

Even families with good incomes may face devastating costs with the illness of a child, especially if the need is for long-term care or treatment not covered by traditional insurance policies. A 1986 study by the United Cerebral Palsy Association depicts the costs commonly associated with this chronic condition, and the amount borne by the family:

- For surgical procedures, private insurance pays up to 80 percent
- Expenses for wheelchairs, braces, and special adaptive devices represent a continual drain on family resources; the equipment purchased by many families is "dictated by availability of funds rather than...the need"
- Families usually bear the entire cost of making a home accessible to a handicapped child
- Special transportation costs are also met almost exclusively by families

Current expenses, including doctor bills, speech therapy, and medication average $4490 annually, with 51 percent paid by the family. Such families face the burden of continuing and accumulating health care costs which in sum, are catastrophic

The uninsurable population is comprised of individuals, both children and adults, whose health status precludes them from obtaining health and life insurance. This population is increasing as demographics demonstrate the gradual aging of America and the increasingly successful application of medical technology. People who previously died from serious diseases are now able to live with those diseases, yet often with a constant drain on their resources and exclusion based on medical history, from affordable insurance protection.

Approximately nine percent of Americans have a serious illness, and one to two percent of all children in America have a severe chronic illness. A 1986 study by Communicating for Agriculture shows that of rural Americans surveyed in five states over the past three years, 10 percent had been denied health insurance because of health status.

Principles of a Policy for Children

A number of basic principles can be identified that guide recommendations for a solution to catastrophic illness expense for children:

- This issue is primarily one of equity and access to care for all children
  - Medical science has shown what can be achieved when children receive adequate preventive, palliative, and anticipatory services
  - Society responds positively in individual cases, such as when pleas are made to extend all that medicine can offer, as in the case of organ transplants
  - It is ethically unacceptable that care be available only to those with resources to pay
  - Society has deemed the elderly entitled to appropriate and necessary health care through the Medicare Program. To assure that the

generations are not divided arbitrarily, children deserve the same consideration

- The issue is one of maintaining family integrity and stability
  - Care should be provided in the setting that maintains and encourages a stable family situation
  - When a child is ill, the whole family feels the impact, both socially and economically. A goal of public policy must be to ameliorate the economic disruption of the family, which is a leading cause of family disintegration
  - Public policy in welfare reform and education has stressed the importance of maintaining the fabric of the family. Health care policy deserves the same emphasis
- The issue encompasses more than high-technology, expensive care
  - Public policy must respond to the variety of situations that can be considered catastrophic. Primary care needs for the poor and chronic care needs must be met as well as the needs of the severely ill child
  - As the problem has no single cause, the solution will not come from a single resource. Public policy must draw on all facets of society, incorporating efforts by both the private and public sectors, and the family
- Safeguarding the health of children is an investment in the future
  - There is a compelling interest on the part of government to ensure the safety and well-being of children, so that future generations will be at least as stable and independent as the present
  - There is likely always to be a segment of society that cannot adequately provide for itself, and must turn to the public for assistance
  - We demonstrate our worth as a society by providing for those who are most in need--including those children who suffer from catastrophic illness expense
- The issue resolution must not overlook the current need to be budget-realistic
  - Public, Congressional, and Executive commitment to a balanced budget and reduction of the federal deficit is clear

Public and Private Initiatives to Reach Children in Need

Employment-related health insurance remains the dominant mechanism for protecting the working population. To protect against catastrophic illness expense, public policy initiatives to strengthen this resource must include:

- The requirement that all employers provide a minimum health benefits package for employees, including prenatal and child health care
- The development of state level insurance pools for participation by small employers, self-employed, and seasonally-employed people. Allow, if actuarially sound, uninsurable people to purchase from this pool; or
- The establishment, if necessary, of separate state risk pools for the uninsurable
  - The basis for such pools is an association of all insurers in the state. By amending ERISA, companies that self-insure should also be included in financing the pool. A choice of deductibles and extent of coverage beyond a required minimum with varying premiums would be available from which the purchaser might choose

- The development of state or regional catastrophic insurance pools where such coverage is not provided or cost effective for small employers or risk pools which include:
  - a full range of necessary institutional services for therapeutic purposes
  - home health care; including coverage for adaptive services, transportation and support services
- The encouragement of other insurance pools to buy into the catastrophic pool along with other beneficiaries to maximize risk-sharing
- The allowing of tax deductibility of employer paid health insurance premiums only with provision of catastrophic protection or their participation in the catastrophic insurance pool
- The taxation of employees on their health insurance benefits unless they cover their dependents; alternatively, disallow a portion of their standard deduction for dependents unless those dependents are included in their insurance benefit
- The protection of the poor and many of the near poor through comprehensive expansions in the Medicaid Program including:
  - mandating coverage for pregnant women and children under age six whose incomes are below the federal poverty level; and
  - eliminating state-to-state discrepancies with regard to eligibility and the extent of services provided
  - requiring that any savings to the states in the Medicaid program accruing from Medicare changes be maintained within Medicaid
- The inclusion of children in any demonstration project or study of catastrophic coverage
  - Secretary Bowen recommends a long-term care study for the elderly; this study should include children with long-term care needs
  - Secretary Bowen recommends a demonstration project of catastrophic benefits for Federal employees; such a demonstration should include children
- The initiation by the Federal Government of a new study of health care costs, utilization, and resources that includes children
  - Current aggregate, national data of this nature are lacking, with the NMCES study now ten years old

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ROBERT H. SWEENEY
President

FACT SHEET

THE NATURE OF CHILDREN'S CATASTROPHIC HOSPITAL EXPENSE

Catastrophic illness expense depends on care costs relative to a family's resources and health insurance coverage. Complete data, however, do not exist. The analysis below uses a simple method to identify catastrophic expense: a hospital stay where hospital charges exceed $50,000. Maryland data serves as a proxy for the U.S. because of similar hospital patterns.

Few hospitalized children incur catastrophic expenses:

- 0.21% of children hospitalized in Maryland in 1984-5;
- 1.35% of admissions to children's hospitals in 1983-4.

Children's catastrophic hospitalizations are long and expensive:

- Catastrophic stays in children's hospitals average 87 days and $105,600 in hospital charges;
- Catastrophic stays in Maryland hospitals average 110 days and $92,900 in hospital charges.

Newborn babies are the largest category of catastrophic cases:

- 65% of Maryland catastrophic cases are newborns; of these, 54% are premature infants and 46% full-term babies (over 5.5 lbs.) with major problems;
- 50% of children's hospital catastrophic cases are newborns; of these, 73% are premature infants and 27% are full-term babies with major problems;
- 10% of catastrophic cases in children's hospitals have nervous system problems; heart, respiratory, and digestive system problems each account for 5-7%.

Catastrophic care for children consumes a high proportion of hospital resources:

- 26.3% of total children's hospitals inpatient charges are incurred by the 1.35% of cases which are catastrophic.
- 8.0% of all care in children's hospitals is uncompensated.

3/87

The National Association of Children's Hospitals and Related Institutions, Inc.
401 Wythe Street, Alexandria, Virginia 22314
Phone (703) 684-1355

PEDIATRIC DISCHARGES FROM A NATIONAL SAMPLE OF CHILDREN'S HOSPITALS 1983-84

DISTRIBUTION OF INPATIENT CASES AND CHARGES BY RANGE OF CHARGES AND CHDC
PHASE IV CHDCS FOR 12 CHILDRENS HOSPITAL SAMPLE 10:26 THURSDAY, FEBRUARY 28, 1987 18
EXCLUDES ADULTS, DELIVERY, NORMAL NEWBORNS, SAME DAY CARE, AND CHARGES < $100/DAY

****** ALL CHDCS ******

ACTUAL CHARGES	NUMBER OF CASES	PERCENT OF CASES IN CHDC	TOTAL CHARGES	PERCENT OF CHARGES	AVERAGE CHARGES	HIGHEST CHARGE	TOTAL DAYS OF CARE	PERCENT OF DAYS	AVERAGE LENGTH OF STAY	LONGEST STAY
TOTAL	84761	100.00	480 637 333	100.00						
UNDER $5 000	66767	78.77	125 081 268	27.19	1873.96	4999.86	951 103	100.00	6.57	922
$5 000 - 9 999	9081	10.73	61 301 361	13.76	6961.08	9999.49	203 232	36.48	3.04	38
$10 000 - 24 999	6111	7.09	90 898 610	19.73	14722.05	24998.62	96 490	15.52	9.51	56
$25 000 - 49 999	1766	2.06	60 121 990	13.05	34413.62	49962.96	101 401	18.20	17.87	109
OVER $50 000	1148	1.35	121 233 864	26.33	105604.41	846108.93	60 179	10.79	34.48	266
							99 881	17.93	87.00	922

ACTUAL CHARGES+OVER $50 000

CHDC #	CHDC DESCRIPTION	NUMBER OF CASES	PERCENT OF CASES IN $ RANGE	TOTAL CHARGES	PERCENT OF CHARGES IN $ RANGE	AVERAGE CHARGES	HIGHEST CHARGE	TOTAL DAYS OF CARE	PERCENT OF DAYS IN $ RANGE	AVERAGE LENGTH OF STAY	LONGEST STAY
	****** ALL CHDCS ******										
0 0	*** INVALID DISCHARGE DIAGNOSIS ***	1148	100.00	121 233 864	100.00	105604.41	846108.93	99 881	100.00	87.00	922
1 0	1 = NERVOUS SYSTEM	7	0.61	1 209 562	1.00	172794.57	846108.93	1 021	1.02	145.86	702
2 0	2 = EYE	117	10.19	12 494 185	10.31	106783.03	821262.27	9 989	10.00	85.38	922
3 0	3 = EAR, NOSE AND THROAT	1	0.09	112 147	0.09	112146.64	112146.64	42	0.04	42.00	42
4 0	4 = RESPIRATORY SYSTEM	14	1.22	1 748 195	1.44	96613.92	278012.84	777	0.78	55.50	163
5 0	5 = CIRCULATORY SYSTEM	72	6.27	10 086 892	8.32	140067.80	651844.19	7 116	7.12	98.16	616
6 0	6 = DIGESTIVE SYSTEM	83	7.23	8 465 630	6.98	101995.54	610874.16	4 569	4.55	54.81	227
7 0	7 = HEPATOBILIARY SYSTEM & PANCREAS	56	4.88	6 471 261	5.34	115558.23	651385.19	5 292	5.30	94.52	733
8 0	8 = MUSCULOSKELETAL SYS, CONNECT TISSUE	13	1.13	1 311 728	1.08	99286.78	254818.75	778	0.78	59.69	96
9 0	9 = SKIN, SUBCUTANEOUS TISSUE, BREAST	22	1.92	1 768 206	1.46	80418.45	178274.38	1 898	1.90	86.27	214
10 0	10 = ENDOCRINE, NUTRITIONAL, METABOLIC	7	0.61	561 710	0.46	84816.32	153479.94	487	0.48	69.86	198
11 0	11 = BLDDR, AND URINARY TRACT	26	2.26	3 815 521	3.20	149058.58	339874.89	3 291	3.29	126.58	562
12 0	12 = MALE REPRODUCTIVE SYSTEM	12	1.05	1 031 107	0.86	86425.58	328098.12	930	0.93	66.11	61
13 0	13 = FEMALE REPRODUCTIVE SYSTEM	1	0.09	180 484	0.11	130484.33	130484.33	93	0.09	81.00	93
15 0	15 = NEWBORNS	2	0.17	196 308	0.16	78153.88	86626.64	172	0.17	86.00	119
16 0	16 = BLOOD, BLOOD FORM ORGANS, IMMUNITY	571	49.74	98 014 926	48.53	101658.11	889501.62	49 787	49.86	87.21	908
17 0	17 = MYELOPROLIFERAT DIS, MISC MALIG.	14	1.22	1 226 619	1.01	87615.25	163048.88	641	0.64	45.78	77
18 0	18 = INFECT & PARASITIC DIS SYSTEMIC	36	3.14	3 410 283	2.81	94730.08	234902.81	2 004	2.01	55.67	150
19 0	19 = MENTAL DISORDERS	10	1.22	1 183 182	0.98	77363.03	137133.08	621	0.62	62.10	151
21 0	21 = INJURY, POISON, TOX EFFECT OF DRUG	26	3.14	2 550 196	2.83	98622.11	179045.03	1 613	1.62	62.04	301
22 0	22 = BURNS	23	2.00	2 088 366	1.72	90798.51	177351.45	1 706	1.71	74.17	419
23 0	23 = MISC CONTACT WITH HEALTH SERVICES	9	0.78	891 128	0.74	99080.96	211848.00	662	0.66	73.56	165
24 0	*** UNGROUPABLE ***	10	0.87	761 455	0.63	76145.51	148903.83	861	0.86	86.10	116
		2	0.17	118 882	0.10	59440.93	97682.49	161	0.16	80.50	82

272

277

PEDIATRIC DISCHARGES FROM ALL MARYLAND HOSPITALS 1984-85

DISTRIBUTION OF INPATIENT CASES AND CHARGES BY RANGE OF CHARGES AND CMDC — 18
*** MARYLAND DISCHARGES 1984 - 1985 *** — 17:10 WEDNESDAY, FEBRUARY 25, 1987
EXCLUDES ADULTS, SAME DAY CARE, AND CHARGES < $100/DAY

****** ALL CMDCS ******

ACTUAL CHARGES	NUMBER OF CASES	PERCENT OF CASES IN CMDC	TOTAL CHARGES	PERCENT OF CHARGES	AVERAGE CHARGES	HIGHEST CHARGE	TOTAL DAYS OF CARE	PERCENT OF DAYS	AVERAGE LENGTH OF STAY	LONGEST STAY
TOTAL	218152	100.00	373,138,069	100.00	1705.71	655599.00	917.307	100.00	4.18	633
UNDER $5,000	208056	95.11	216,548,806	58.03	1040.68	4999.00	648,951	70.70	3.12	35
$5,000 - 9,999	6491	2.97	45,031,806	12.07	6937.59	9994.00	96,180	10.49	14.82	79
$10,000 - 24,999	2631	1.20	35,716,917	9.57	13574.65	19998.00	68,410	7.46	26.02	111
$25,000 - 49,999	1117	0.51	31,399,179	8.95	24900.79	49924.00	54,036	5.89	48.37	214
OVER $50,000	457	0.21	42,463,361	11.38	92917.42	655599.00	50,072	5.46	109.57	633

ACTUAL CHARGES>$50,000 *

CMDC #	CMDC DESCRIPTION	NUMBER OF CASES	PERCENT OF CASES IN $ RANGE	TOTAL CHARGES	PERCENT OF CHARGES IN $ RANGE	AVERAGE CHARGES	HIGHEST CHARGE	TOTAL DAYS OF CARE	PERCENT OF DAYS IN $ RANGE	AVERAGE LENGTH OF STAY	LONGEST STAY
	****** ALL CMDCS ******										
0 0	*** INVALID DISCHARGE DIAGNOSIS ***	457	100.00	42,463,361	100.00	92917.43	655599.00	50,072	100.00	109.57	633
1 0	1 = NERVOUS SYSTEM	1	0.22	68,330	0.16	68330.00	68330.00	416	0.83	416.00	416
3 0	3 = EAR, NOSE AND THROAT	38	8.32	3,216,695	7.58	91904.17	337480.00	3,515	7.02	100.43	389
4 0	4 = RESPIRATORY SYSTEM	1	0.22	120,788	0.28	120788.00	120788.00	105	0.21	105.00	105
5 0	5 = CIRCULATORY SYSTEM	24	5.25	2,340,950	5.51	97539.58	327467.00	2,190	4.37	91.25	290
6 0	6 = DIGESTIVE SYSTEM	6	1.31	376,794	0.89	62799.00	77650.00	329	0.66	54.83	83
7 0	7 = HEPATOBILIARY SYSTEM & PANCREAS	8	1.75	757,621	1.78	94702.88	158325.00	874	1.75	109.25	162
8 0	8 = MUSCULOSKELETAL SYS CONNECT TISSUE	1	0.22	63,228	0.15	63228.00	63228.00	48	0.10	48.00	48
11 0	11 = KIDNEY AND URINARY TRACT	4	0.88	417,688	1.00	99961.86	206440.00	567	1.13	81.00	165
15 0	15 = NEWBORNS	207	64.99	27,746,924	65.25	92287.96	535998.00	25,842	51.58	120.68	633
16 0	16 = BLOOD, BLOOD FORM ORGANS, IMMUNITY	10	2.19	964,275	2.27	96377.50	221106.00	667	1.33	66.70	143
17 0	17 = MYELOPROLIFERAT DIS, MESC MALIG	36	7.88	3,517,207	8.42	99366.86	622982.00	1,998	3.97	55.22	170
18 0	18 = INFECT & PARASITIC DIS SYSTEMIC	3	0.66	260,112	0.61	86704.00	131677.00	241	0.48	82.33	162
19 0	19 = MENTAL DISORDERS	10	2.19	735,698	1.73	73569.80	158403.00	2,015	4.02	201.50	620
21 0	21 = INJURY, POISON, TOX EFFECT OF DRUG	6	1.31	393,911	0.93	65651.83	100320.00	319	0.64	53.17	69
22 0	22 = BURNS	5	1.09	148,802	0.35	29760.40	84000.00	292	0.58	58.40	89
23 0	23 = MISC CONTACT WITH HEALTH SERVICES	3	0.66	256,652	0.60	118884.00	120198.00	275	0.55	91.67	101

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ROBERT H. SWEENEY
President

CATASTROPHIC ILLNESS EXPENSE AND CHILDREN

To date, attention on catastrophic illness has focused on the elderly population. But for a family, a child's illness or injury can be just as catastrophic as that of a grandparent. When a family is unable to provide adequate care for a child due to lack of resources, health care expenses are catastrophic.

No one is immune from illness expense of catastrophic proportions. This occurs in part because of the high technology, high cost care now available, where previously no treatment was possible.

Catastrophic illness expense in the pediatric population may occur in three instances: acute care (premature birth, accidents); chronic care (cancer, rehabilitation); and primary care (emergency care, minor surgery).

Private and public sector initiatives are needed:

- Require employers to provide a minimum health benefit package for employees which includes prenatal care and coverage for children.
  - Establish state level insurance pools for small employers; self-employed or seasonally-employed individuals; and, if actuarially feasible, the uninsurable population.
- Establish state or regional catastrophic insurance pools to supplement the minimum private insurance policies.
- Provide tax incentives to encourage the coverage of children and the use of the catastrophic insurance pools.
- Mandate Medicaid coverage for pregnant women and children under age six whose incomes are below the Federal poverty level.
  - Provide that any savings to the states in the Medicaid program resulting from changes in the Medicare program be maintained within Medicaid.
- Eliminate state-to-state discrepancies in Medicaid eligibility and services.
- Include children and young adults in demonstration projects and studies of catastrophic insurance coverage conducted by the federal government.

The National Association of Children's Hospitals and Related Institutions, Inc. 3/87
401 Wythe Street, Alexandria, Virginia 22314
Phone (703) 684-1355

9 Catastrophic Illness Cases in a Children's Hospital
Presented by the National Association of Children's Hospitals and Related Institutions

	All Admissions	Total Bill	Source	Amt. Collectible	Difference
AMANDA	7 Admissions 12/22/84 - Present	$1,119,255.13	Ins. Co. A Ins. Co. B Title 19	$500,000.00 $395,419.13 $ 20,665.00	$ 203,171.00
Skull/facial and extremity malformations, chronic lung disease (bronchopulmonary dysplasia = BPD).					
HILIARY	6 Admissions 8/5/86 - Present	$ 230,274.24	HMO A Title 19	$158,898.91 8,348.00	$ 63,027.33
Hemorrhage into brain.					
DUSTIN	2 Admissions 12/28/85 - Present	$1,052,856.56	Ins. Co. C	$246,949.00	$ 805,907.56
Bronchopulmonary dysplasia					
JERRY	1 Admission 10/13/86 - 12/24/86 (Died)	$ 133,105.81	Title 19	$ 4,133.00	$ 128,972.81
Prematurity anoxic brain damage.					
ANDREW	1 Admission 10/26/86 - Present	$ 329,844.16	Ins. Co. D	$257,923.00	$ 71,921.16
Heart not covered with bony thorax.					
MARKEL	1 Admission 8/25/86 - Present	$ 355,598.25	Title 19	$ 4,174.00	$ 351,424.25
Joint contractures of fingers, knees, hips, elbows, ankles.					
CONNIE	1 Admission 9/21/86 - Expired	$ 317,057.30	Ins. Co. F	$224,079.00	$ 92,978.30
Severe malformations of colon, rectum, abdominal wall, pelvis and bladder					
DANIEL	1 Admission 12/19/85 - 12/6/86 (Died)	$ 896,603.13	HMO B Medicare	$558,737.09 $337,866.04	$ -0-
Polycystic kidney with chronic renal failure.					
JOSEPH	1 Admission 1/9/86 - 12/5/86 (Expired)	$ 766,050.12	Title 19	$ 4,133.00	$ 761,917.12
Umbilical hernia atresia & stenosis of large intestine, anomaly of genital organs, anomaly of musculoskeletal system, patent ductus arteriosus					
	TOTALS	$5,200,644.70		$2,721,325.17	$2,479,319.53

NATIONAL ASSOCIATION OF PERINATAL SOCIAL WORKERS

mailing address:
Sally A. Mack, LICSW
111 Beverly Road
Chestnut Hill, MA 02167
(617) 469-9308

March 31, 1987

Representative George Miller
Chairman,
Select Committee on Children, Youth
and Families
Room 385
House Office Building, Annex 2
2nd and "D" Streets, S.W.
Washington, D.C. 20515

Dear Representative Miller:

The National Association of Perinatal Social Workers represents the interests and concerns of approximately 2,000 professional social workers who work with high risk child-bearing families, including those families who have seriously ill infants and children. A large percentage of these children have chronic disabling conditions which conditions which could be managed on an outpatient basis and at home if there were catastrophic health insurance available.

At present our high technology medical system is able to save critically ill children, including premature newborns, who subsequently can be kept alive and maintained only with on-going medical support. If these children are to be raised in their own homes, they often need costly equipment and service such as respirators, physical therapy and transportation to medical facilities. Furthermore, the energy and time (sometimes up to 24 hours a day of attention) that the care of these children demands necessitates that parents must have home nursing or respite care so that

they can avoid surrendering their child to the care of an institution.

The lack of catatrophic health insurance programs results in many otherwise unnecessary hospitalizations or institutionalizations. As a result, the quality of life for these children and families is severely compromised. In fact, when the institution involved is located far from the family's home or the family does not have resources to travel and visit their child, some of these children who otherwise could have lived at home see their families as little as a few time a year.

Besides the emotional and psychological toll that lack of health insurance problems present, the cost of institutional care is much greater than out-patient and home care programs and the resulting economic costs to the community and government agencies are greatly increased.

We would appreciate having this letter included in the record of the hearing which took place on March 23d. If we can provide further information or clarification, please call upon us. Thank you for your attention to these matters.

Sincerely yours,

Sally A. Mack

Sally A. Mack, LICSW, Chair
Social Action Committee
National Association of Perinatal
Social Workers

PROJECT ABC

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Executive Director
Marian Sokol, Ph.D.

March 25, 1987

Congressman George Miller
Chairman
Select Committee on Children, Youth, and Families
U.S. House of Representatives
385 House Office Building Annex 2
Washington, D.C. 20515

Dear Congressman Miller:

Project ABC has been informed that you are considering sponsoring legislation for a catastrophic health insurance program for children. We are very aware of the need for such a program for our medically-involved chronically-ill (MICI) babies and would like to provide you with information to document this need. We are seeing more and more families becoming financially destitute due to the high cost of medical care for their children.

We would be more than happy to provide you with additional information if needed. Thank you for your continued support of special children.

Sincerely,

Marian Sokol, Ph.D.
Director
Project ABC

Jennifer M. Cernoch, Ph.D.
Director
Texas Respite Resource Network

THE CHILDREN'S HOSPITAL AMBULATORY CARE CENTER
519 W. Houston • Post Office Box 7330, Station A • San Antonio, Texas 78285 • (512) 228-2 ABC
PROJECT ABC IS A SUPPORT CENTER FOR FAMILIES OF HANDICAPPED AND CHRONICALLY ILL CHILDREN

United Way

Project Any Baby Can (ABC), located at Santa Rosa Children's Hospital in San Antonio, Texas, is a Support Center for families who have children with special needs. Project ABC was founded in 1982 to help relieve some of the stresses experienced by parents of handicapped, chronically ill, and medically-fragile young children. Project ABC links families with more than 300 South Texas agencies and acts as an information center for families who many times, are emotionally and economically drained and do not know where to go, what to ask, and whom to turn to for help for their special children. Along with the information, referral, and case management services, Project ABC offers direct support services including a crisis fund for infants, emergency formula distribution, infant monitor loan program, trained babysitters, carseat loan program, Foster Grandparents and Family Friends, speech and hearing screening, and Pedi-organ donor awareness efforts. Project ABC offers assistance that other social service agencies do not provide. The main goal of ABC is to meet the needs of families with special children.

Over the past two years, Project ABC has observed increasingly critical emerging needs in the area of assistance for families of the medically-involved chronically-ill (MICI) babies. With the advances in medical technology, rising medical costs, and new federal and state regulations regarding DRG's and Medicaid, many children are being released from hospitals without the support services to maintain these children at home. In the past, Project ABC was receiving calls from families seeking primarily therapeutic or educational interventions for their child. Now, however, the calls received are from families seeking assistance in purchasing medical equipment and supplies, buying specialized formula for their premature infant, paying for in-home skilled nursing care for their child who is on life-support equipment, finding qualified help (day care options) so that the parent can remain working to keep health insurance benefits, and purchasing basic needs such as food, clothing and utility costs.

So many ABC families are financially devasted at the cost of maintaining their medically fragile child at home yet, institutional care can cost three times that of in-home services. Many ABC parents have had to quit their jobs because of the lack of in-home support services, thus losing their health insurance benefits. Many ABC children have exhausted their insurance benefits by the time they reach 2 years of age. And unfortunately for some ABC families, bankruptcy has been the only answer in providing medical needs for their special child.

Project ABC is acutely aware of the need for extended health coverage for the MICI babies and for the need of subsidies for in-home support services. Families and programs such as Project ABC are facing a critical step financially in preserving and improving the quality of life for the medically-fragile child.

With permission from the families, Project ABC has written narratives about

two San Antonio families that would benefit from a catastrophic health insurance program or from subsidies made available for in-home support services for their medically involved children. These narratives are provided as information documenting the need for increased services to families and the need for agencies such as Project ABC to provide the services.

Family # 1:

Adam and Alex are 15 month old multi-handicapped twins, who have accumulated several hundred thousand dollars of medical expenses since birth. Alex's problems are severe, and include blindness, cerebral palsy and seizures. Adam is doing fairly well at present, and his colostomy has been reversed. He still lags in development and is prone to respiratory infections. There are two other young children, Andrew and Albert ages 4 and 5 years old in the family. Dad recently was involved in an auto accident and hospitalized; their truck was totally destroyed in the accident. Due to this and other pressures, mother had to resign her job, and now there is no insurance to cover the medical costs. Because this couple was working and not indigent, there is little in state and federal funds to cover any of their expenses. Project ABC has assisted this family by providing in-home support services through our Foster Grandparent Program, by purchasing a twin stroller, by supplying medical supplies and infant formula, and by adopting the family in our Adopt-A-Family Christmas effort.

Family # 2:

Justin, who is two years old, was born with multiple problems which has resulted in cerebral palsy on one side of his body, seizure disorders, and autistic-like behaviors. Justin's primary problem is encephalopathy: a progressive brain degeneration of unknown cause. Because of his brain damage, Justin's behaviors are many times violent causing him to hurt himself and his brother and mother. Daily, Justin is on numerous medications to control his seizures and behavior. A recent severe reaction to his phenobarbital medication caused additional problems when burns, blisters, and eye damage covered Justin's body. Justin's mother is a single parent who has lost three jobs - and consequently health insurance coverage - due to missing work caring for Justin. Justin's severe medical conditions require him to see six physicians a month. Currently, the family has more than $65,000.00 outstanding in medical bills. Project ABC has assisted this family by purchasing medications, securing funds for a bubbletop crib, and providing respite services.

In addition to these two families, Project ABC has assisted over 600 medically-involved, chronically-ill children and their families in 1986. Project ABC's services are diversified and individualized to meet the needs of families. Because of the economic stresses placed on these families, Project ABC's services

are provided at no cost to the families. Project ABC has also assisted:

- Family of Baby Nicky (double heart transplant) who needed air transport, food and lodging in California. Baby Nicky died on July 2, 1986 at Loma Linda University Medical Center and Project ABC was able to secure funds to transport Nicky back to San Antonio and arranged all funeral services.
- Family of Baby Moses who needed a suctioning machine, oxygen, trach supplies, prescription formula, and basic essentials such as food, clothing and utility costs. Project ABC was able to provide these services so that Moses could spend Christmas at home. Upon his death, Project ABC was able to secure donated funeral services for Moses.

PROJECT ABC

Marion Sokol, Ph.D
DIRECTOR

Project Any Baby Can

HIGHLIGHTS

1986

BABY HELPLINE

* Staff case managed 685 new children resulting in more than 840 referrals to South Texas agencies.
* Responded to over 250 requests for emergency assistance including infant monitors, life support equipment, and prescriptive infant formula.
* Disbursed more than $20,000.00 in Crisis Fund Assistance to families of special children; used for necessities such as oxygen, medical supplies, emergency housing and funeral expenses.
* Provided approximately 5,800 hours of respite, or relief care, with ABC Foster Grandparents, high school babysitters and nurses.
* Provided free monthly speech and hearing screening for more than 125 children under age three.

ADVOCACY

* Established Children's Transplant Association of South Central Texas and spearheaded organ donor transplant efforts on behalf of several children.
* Sponsor of the Texas Respite Resource Network, a special component of ABC, which provides technical assistance in issues of respite care. Hosted statewide conference with attendance of more than 300 professionals and parents.
* Advocacy on behalf of babies at risk for Sudden Infant Death Syndrome and sponsorship of ABC Apnea Monitor Loan Program.
* Testimony throughout state addressing respite care and medicaid issues affecting handicapped and chronically ill children.
* Coordinated meetings of task force on teen pregnancy 1985-86, which resulted in new San Antonio grant to address pregnancy recidivism in teens under age 17.
* Distributed more than 4,000 "Watch Me Grow" developmental checklists.

SPECIAL EVENTS

* Hosted Crisis Fund Benefit in conjunction with Humana Women's Hospital featuring Dr. T. Berry Brazelton; raising more than $5,000.00 for ABC Crisis Fund.
* Coordinated "ABC Adopt a Family" Christmas effort, resulting in sponsorships of more than forty families with food, clothing, medical supplies and toys.
* Taught U.T. Health Science Center Medical Student course, Psycho-Social Dimensions of Health Care.
* Project ABC selected as recipient of Robert Wood Johnson Foundation Demonstration Grant which will establish "Family Friends" program to link trained senior citizens for in-home support of families with handicapped and chronically ill children.

THE CHILDREN'S HOSPITAL AMBULATORY CARE CENTER
Post Office Box 7330, Station A • San Antonio, Texas 78285 • (512) 228-2-ABC
FOUNDED BY THE SAN ANTONIO COALITION FOR CHILDREN, YOUTH AND FAMILIES

PROJECT ABC

Marion Sokol, Ph.D.
DIRECTOR

ABC Baby Helpline Update
December 1986

As 1986 came to a close the Project ABC staff reviewed new cases which had been opened and noted the following information:

*Staff case-managed 677 new children resulting in more than 840 referrals to over 300 South Texas agencies.

*Responded to over 250 requests for emergency assistance including infant monitors, life support equipment, and prescriptive infant formula.

*Disbursed more than $20,000.00 in Crisis Fund Assistance to families of special children; used for necessities such as oxygen, medical supplies, emergency housing and funeral expenses.

*Sponsored 220 children in city-wide Adopt-a-Child Christmas effort, whereby San Antonio businesses and organizations supplied families with more than $15,000 worth of food, clothing, medical supplies and toys.

Staff also noted the following trends, which ultimately will compound the problem of meeting client needs during the year ahead:

*Current cuts in Medicaid and rising medical costs are placing pressure on hospitals to send babies home sooner. In-home care of medically involved children presents serious economic problems, as well as emotional strain on families. In addition to medical supplies uncovered by Medicaid (such as oxygen); the increase in utility costs caused by life support equipment and the need for telephones in home and skilled nursing care are major obstacles to a middle class or poor family with a chronically ill child.

*ABC families are worried about basic needs: choices of whether to pay for food or physician care; concerns about replacing poorly functioning medical equipment, money for funerals, and essentials such as ostomy bags and feeding tubes are a reality.

*The organ transplant population is growing and physicians and parents are turning to Project ABC for help. Medical technology can save many children (success rate over 70%).

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Our families need basics such as money to travel to the transplant site. (Bottom line is: Given the choice; "Is there any parent who would not try every avenue possible to save his or her child??").

*Many families cannot afford the nutritional needs of their babies. Project ABC purchases and distributes more than $8,000 worth of prescriptive formula per year. The average price per case of six cans is more than $60. Project ABC twins often consume $500 worth of special formula per month. Several babies on hyperalimentation require $2,000 of nutritional support per month to sustain them. Families are often on waiting lists for the WIC programs, or disqualified if child is not underweight.

*Dealing with San Antonio social service agencies or our community churches for donations of food or small contributions toward utility bills, is not a realistic option for many ABC families. Indigent families do not have autos, and most cannot take a sick child on buses. The most serious problems are those families where a single parent with several children has a baby on life support equipment and cannot leave the house.

In summary: Project ABC is on the cutting edge of an emerging population of babies who are surviving better than before, but going home with specialty needs to families which are unable to meet both medical expenses and the basics of food, formula and utilities. Our population increases as Medicaid cuts and hospital cost containment send babies home sooner; and as technology provides more options for infants to survive, as with transplants and hyperalimentation, at a cost beyond affordability for most families.

PREPARED STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION

INTRODUCTION

The issue of catastrophic health care coverage for Americans of all ages is of great concern to the American Hospital Association's 5,600 institutional and 40,000 personal members. We are pleased to have this opportunity to present our views on the problem of catastrophic care for children. Each year, thousands of families face financial ruin because one of their members incurs health care expenses that are not covered by insurance and are beyond the family's ability to pay. When this happens, a serious illness becomes a financial catastrophe for the entire family. Most Americans are protected against the cost of acute medical care through private insurance, Medicare, or Medicaid. But 37 million Americans face a financial catastrophe from any serious illness because they lack any form of insurance. In addition, up to 20 million of the non-Medicare insured population also may be at risk for catastrophic acute care costs because of limitations on private insurance coverage. Even in the Medicare population, a substantial amount of acute care must be paid out of pocket because of Medicare coverage limitations.

Although all age groups are affected by the catastrophic care problem, the reasons differ from one group to another. For the elderly and disabled, catastrophic expenses result from two gaps in health insurance coverage: inadequate Medicare coverage of catastrophic acute care costs and even more inadequate public and private coverage of long-term care costs. For children and non-elderly adults, on the other hand, catastrophic expenses usually result from a combination of poverty and non-existent or inadequate insurance, and therefore even relatively minor illnesses and even modest medical bills can be financially catastrophic.

Catastrophic care for the elderly and disabled is a serious national problem, one we discussed in detail during our March 19 testimony before the Senate Finance Committee. But concern over the problem of catastrophic illness among the Medicare population should not draw attention away from the significant problem of medical indigence in the non-Medicare population. Our testimony today concentrates on needs of the non-Medicare population, and in particular on the problem of catastrophic care for children.

CATASTROPHIC CARE FOR CHILDREN:
EXAMPLES OF THE PROBLEM

Few children require medical care that results in catastrophic expenses to their families. In any given year, fewer than one million children--1 percent of all children under 21--are likely to incur out-of-pocket medical expenses greater than 10 percent of family income. When children do require catastrophic care, however, it can be very expensive, and costs frequently will exceed available insurance. Recent case histories from hospitals around the country illustrate the range of pediatric catastrophic care needs:

- A 1-year-old girl was admitted with a diagnosis of meningitis. Her father was employed and had company insurance, but no dependent coverage. The father withdrew $2,500 from an IRA to pay toward her care. After the first two weeks of hospitalization, the bill already had reached $26,677.

- A 4-year-old boy was admitted after post-surgery aspiration. The child was comatose. The single mother was employed, but her company offers no group insurance. The mother applied for assistance but was denied due to her income level. The child will have long-term, complex continuing care needs. After one month of hospitalization, the family owed $70,539.97.

- A 5-year-old girl was admitted with seizures, and later was diagnosed as having a malignant brain tumor. Her father is self-employed, with no insurance coverage. She may be eligible for Medicaid spend-down and state crippled children's funds. After one month of hospitalization, the expenses have reached $32,237.

- A 14-year-old boy was admitted with a self-inflicted gunshot wound. His father is a self-employed carpenter without health insurance. The family applied for Medicaid spend-down, but may not meet eligibility requirements. The family already owes $127,661 for the first month of hospitalization.

- A newborn boy was born prematurely. His mother is single, employed, but with no group insurance. The boy may be eligible for Medicaid spend-down. The infant will require two to three months of hospitalization. After one month, the bill already is $53,223.

CATASTROPHIC CARE FOR CHILDREN:
DIMENSIONS OF THE PROBLEM

Catastrophic illness is an individual human problem, which also becomes a family and community social problem. When a child has an acute or chronic disabling condition, whether as a result of birth, illness or accident, it is clearly a catastrophe. Because these conditions usually are costly, they often generate bills that tax or exceed the family's ability to pay and therefore result in catastrophic or uncompensated medical expenses. Even for families with private insurance, a traumatic childhood illness or a serious chronic disease or disorder can result in financial catastrophe for the family, either through increased out-of-pocket expenses or through wages lost because of time spent with an ill child.

Catastrophic Illness

Many catastrophic childhood illnesses or conditions can generate sizable acute care costs quickly. For example, the National Association of Children's Hospitals and Related Institutions has testified that:

- Approximately 220,000 premature babies are born each year; with intensive care nursery charges approximately $1,000/day, average hospital charges are over $35,000 for an immature infant.

- Heart surgery for a child may cost a family $22,000 for a hospital stay.

- Treatment for extensive burns may result in a hospital bill of $45,000.

In addition, many children face chronic care needs, have a cumulative effect, and are likely to be coupled with spells of acute illness.

- Comprehensive care for children with cystic fibrosis can cost a family $6,000 - $12,000 annually; intermittent hospitalizations may average over $7,000 per stay.

- Institutional care for a ventilator dependant child may amount to $350,000 annually.

Finally, care for children with mental health problems can be very costly and inadequately insured, and therefore tend to be undertreated. There is general agreement that at least 7.5 million children--12 percent of all children--need some mental health treatment, but less than one-third of these children receive treatment.

Catastrophic Expenses for Non-Catastrophic Illness

While catastrophic acute or chronic illness is one important cause of catastrophic expense, it is not the only cause. In fact, most of the people who incur catastrophic expenses are not victims of catastrophic illness but rather are victims of poverty and lack of insurance.

The magnitude of the problem of financially catastrophic illness largely depends on the definition adopted. Some have defined catastrophic expenditures as those exceeding a specific annual cut-off figure, such as $2,000, but such definitions do not account for differences in income. For this reason, health policy researchers are more likely to use a definition that relates expenditures to income. A common definition is that catastrophic expenditures are those which exceed 10 percent of family income.

For children and non-elderly adults, the major cause of catastrophic expenses is the combination of poverty and non-existent or inadequate insurance. Almost a quarter of the non-elderly population are either uninsured or underinsured and therefore are at risk of incurring catastrophic medical expenses; that is, they have a 5 percent expectation of incurring out-of-pocket expenses exceeding 10 percent of family income. Among the poor and near-poor, over half are at risk. As a result, most catastrophic care expenditures involve relatively modest bills incurred by the poor and uninsured.

- In four out of five cases, catastrophic medical expenditures result from low incomes and poor health insurance coverage, not exorbitant out-of-pocket medical expenses. Four out of every five catastrophic care expenditures are for an amount under $2,000. Only 5 percent of families with catastrophic expenditures have bills over $4,000.
- Of families spending 10 percent of their income on medical care, half are below the poverty level. Of families spending 20 percent of their income on medical care, two-thirds are below the poverty level.

Children comprise a large segment of the uninsured:

- One-third of all uninsured people under 65 are children.
- In 1984, 12 million children under age 18 were uninsured.

Despite the existence of Medicaid, children constitute an even larger segment of the uninsured poor:

- About 40 percent of the uninsured poor are children.

- In 1984, about 5.5 million children under age 18 were uninsured and poor.

There are several reasons for this large number of uninsured children. First, the parents and guardians of many of these children are themselves uninsured because they work for employers who do not offer group coverage. Second, in some cases the parents or guardians work for employers who purchase coverage for employees but not dependents, or the bread-winner may purchase individual coverage but be unable to afford coverage for the entire family. These circumstances may account for why more than four million of the 12 million uninsured children live with an insured parent or guardian.

Inadequacy of the Medicaid program is the primary reason for the gap in insurance for children, particularly poor children. Although Medicaid is often thought to be the principal means of financing care for the indigent, it now covers less than 40 percent of the poor. Medicaid must now be viewed principally as a program of supplementary coverage for the aged and disabled medically indigent who are eligible for and receive benefits under Medicare. In 1984, barely one-fourth of Medicaid's expenditures paid for care needed by AFDC children and their families. Three-quarters of Medicaid's expenditures paid for services provided to individuals already covered by Medicare: primary care and other acute care services not covered by Medicare; extended long-term care for Medicare beneficiaries; and Medicare Part B premiums.

RECOMMENDATIONS

Although discussions of the catastrophic care problem frequently focus on the dramatic, relatively rare, acute care expenses of the elderly, the catastrophic care problem is much broader and much deeper, extending to both young and old, insured and uninsured. Even when children and non-elderly adults are identified as part of the catastrophic care problem, policy discussions tend to focus on examples of major accidents, catastrophic diseases or chronic disabling conditions. Though such cases are of deep concern to all of us, in terms of the number of children affected the real catastrophe is the lack of basic coverage and preventive care.

Any comprehensive solution to the problem of catastrophic illness not only must address the gaps in acute and long-term coverage for the Medicare population, but must also seek to increase the availability and adequacy of insurance for children and other non-elderly adults. In March 19 testimony before the Senate Finance Committee, we made several recommendations for

addressing the catastrophic care problems of the Medicare population. However, given the focus of the present hearing on catastrophic care for children, the following points detail our recommendations for the non-Medicare population.

Protecting the Non-Medicare Population

Among the non-Medicare population, the catastrophic care problem takes two forms: inadequate protection against catastrophic expenses for many of the insured, and nonexistent coverage of health care needs for the uninsured. Just as the elderly and disabled can face catastrophic expenses despite their enrollment in Medicare, privately insured children and non-elderly adults also can incur large expenses beyond the limits of their coverage. To address the issue of catastrophic illness among the insured population:

- Insurers and employers should make information on the cost and potential value of catastrophic coverage more widely available; and

- Federal policies should encourage the coverage of catastrophic illness by private insurance.

In terms of the number of people affected, however, the larger health policy problem for the non-Medicare population is the large and growing number of uninsured. Because any significant illness is "catastrophic" for an individual without health insurance, a major priority for both the public and private sectors should be the implementation of methods to reduce the number of uninsured and to strengthen public programs providing coverage for individuals unable to purchase private health insurance.

In February 1986 the AMA Board's Special Committee on Care for the Indigent completed its report, Cost and Compassion: Recommendations for Avoiding a Crisis in Care for the Medically Indigent, which outlined a series of long and short-term public and private initiatives which could be adopted to address the medical indigence problem.

Long-term approaches. Medical indigence is a complex, multi-faceted issue that has no single, or simple solution. Because the public expects needed care to be provided regardless of a patient's ability to pay, all members of society must participate in the financing of care provided to the medically indigent. This public responsibility does not mean, however, that government alone can or will resolve the problem. An enduring solution to the problem of medical indigence will require initiatives by both the public and private sectors to:

- Reduce the size of the medically indigent population through adequate private health insurance; and

- Restructure and extend public programs to finance care for the medically indigent who are unable to obtain private insurance.

Private insurance can be made more widely available through cooperative efforts of federal, state, and local government, private insurers, employers, and providers. But, as competition increases and resources become more constrained, a residual public program is essential to finance care for those who cannot obtain private health insurance. To strengthen the public financing of care for the medically indigent, several actions should be pursued:

- The reorganization of Medicaid into three distinct programs: a program of acute care coverage for the medically indigent who are not eligible for Medicare; a program of supplementary acute care coverage for Medicare beneficiaries; and a program of long-term care coverage for Medicare beneficiaries;

- The gradual strengthening of the federal role in funding Medicaid: a Title XIX trust fund sponsored by a broadly based tax, for example a payroll tax. Such a tax could provide a stable source of funding for Medicaid, would equitably distribute the cost of the program, and, properly structured, could create a positive incentive for employers and employees to obtain private health insurance; and

- Reform of delivery and payment systems: the adoption of innovative payment and delivery arrangements would encourage the efficient use and production of the health care services needed by individuals enrolled in Medicaid.

Short-term approaches. Although the elements of a long-term solution to the problem of medical indigence can be identified readily, adoption and implementation of a comprehensive solution will take time. It is essential that there be no deterioration of existing programs during these deliberations. Moreover, while the debate over the long-term solution proceeds, the issue should be dealt with through several incremental steps that strengthen incentives to provide employer-paid health insurance and that gradually strengthen public programs.

First, the federal government should strengthen, and not reduce, tax incentives that encourage adequate private insurance.

- Individuals should be permitted to exclude employer-paid health insurance premiums from taxable income, or to deduct employee-paid health insurance premiums from taxable income, only if the health insurance policy covers all dependents. Current limitations on the tax deductibility of employee-paid health insurance should be rescinded, and the deduction should be made available to all individuals, not just those who itemize deductions; and

- Health insurance premiums should be deductible as a business expense by employers only if the employer pays for coverage of dependents or offers employees the opportunity to purchase such coverage.

Second, employers should be required to continue insurance coverage for laid-off workers as part of unemployment compensation; states should encourage the formation of multiple-employer insurance arrangements to extend insurance to the self-employed and to employees of small firms; and private insurers, employers, and providers should work to create innovative financing and delivery systems that increase the availability of affordable insurance, particularly for small employers.

Third, the federal government should seek to improve public funding.

- Under no circumstances should the federal government reduce the level of federal funding available to state Medicaid programs, nor should it mandate or allow states to reduce entitlement under Medicaid.

- The expansion of Medicaid eligibility should be accomplished as federal resources permit, with the objective of achieving a uniform standard of eligibility under state Medicaid programs by 1990;

- The federal government should permit states to offer Medicaid coverage to people above the poverty level, with a graduated, income-based premium;

- The federal government should phase in the long-term reforms in Medicaid described above to create a stable, dedicated source of funding; and

- To encourage provider participation in Medicaid and to eliminate the need for private-sector subsidies of Medicaid expenditures, Medicare and Medicaid payment levels generally should be comparable to those for private patients.

Fourth, states, local governments, employers, and hospitals should work to maintain and increase funding and access to care.

- States should maintain eligibility and funding levels for Medicaid and other programs designed to finance care for the indigent. As their resources permit, states should expand Medicaid coverage to include both the medically needy and other segments of the medically indigent population;

- States also should establish risk pools for high-risk or uninsurable individuals in which all insurers and employers should participate;

- Local government should maintain or increase funding for public or other government-supported providers;

- Employers and insurers should work with government to ensure adequate funding for the medically indigent who must rely on public support. If adequate public funding is not made available, employers should work with providers and insurers to establish funding mechanisms for care provided to the medically indigent; and

- Hospitals should maintain their historical commitment to provide care to those who need care, including the indigent; should take appropriate actions to raise public awareness of the implications of purchaser actions on the ability of the hospital to care for the medically indigent; and should work with employers, insurers, and government to develop viable short- and long-term solutions to the problem of medical indigence.

CONCLUSION

Although discussions of the catastrophic medical costs problem frequently focus on the dramatic, relatively rare, acute care expenses of the elderly, the catastrophic care problem is much broader and much deeper, extending to both young and old, uninsured and insured.

Many contend that we, as a nation, cannot afford to address all but a small portion of the problem. We submit that, as an enlightened society, we cannot afford to not address the full scope of the problem. The AHA pledges its support and cooperation in tackling this problem, building step by step toward a comprehensive approach to providing desperately needed relief for all children and adults from the fear of catastrophic illness and expense.

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